THE IMPACT OF HEARING IMPAIRMENT ON THE COUPLE, THE FAMILY AND THE SOCIAL NETWORK

Ruth Morgan-Jones

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ABSTRACT

THE IMPACT OF HEARING IMPAIRMENT ON THE COUPLE, THE FAMILY AND THE SOCIAL NETWORK

This qualitative study investigates the challenges and the problems in marriage when one partner has a hearing impairment and the other hears normally. Such knowledge is intended to help clinicians and researchers to have a more accurate picture of the lives of hearing impaired people in that it incorporates both positive and negative dimensions; and helps to lessen the likelihood that they will project their own negative fantasies on to their patients, clients and respondents.

A method of investigation devised by Elizabeth Bott (1957) using repeated intensive interviewing, was adopted with certain adaptations. Using her approach, with other theoretical material, has produced an ethnographic study which illuminates the interaction between peoples' psychosocial experiences and the medical and audiological nature of hearing impairment. Eleven couples were interviewed ten times and five single people were interviewed five times.

In the analysis of the findings, five major strands emerged: intimate family relationships, social support networks, communication strategies, the nature of care and rehabilitation, and recommendations for social policy. From this work particular psychosocial insights emerged.

The research suggests that although acquired hearing loss is a widespread problem in our society due to the growth in the numbers of elderly people in the population compounded by Noise Induced Hearing Loss, present provision is far from adequate. The provision developed in 1978 failed to address the central fact that hearing loss is not only about a physical process of not hearing, but strikes at the heart of communication, specifically that which takes place within the family and social network. Also services for the hearing impaired have ignored the multi-faceted nature of hearing loss and the need for a complementary holistic approach to encourage rehabilitation and adjustment.

ACKNOWLEDGEMENTS

I am indebted to the inspiration provided by the methodology from Elizabeth Bott's study, Family and Social Network, which made possible the discovery of new ground. Like her, I work best with a group of colleagues with related interests and skills. However, I did not have the resources to emulate her situation exactly so I simulated it, asking the help of a group of colleagues and friends whom I saw on a regular basis sometimes within the traditional supervision/tutorial context, and sometimes over a friendship lunch..

The idea for the project initially emerged when in conversation with Gill Madge of the University of North London. It was nurtured further by Nina Cohen, my long time counselling supervisor at the Tavistock Institution of Marital Studies. Her understanding, insight and support with the transition from counsellor to researcher was invaluable. Simultaneously, I began working with Sally Sainsbury at the London School of Economics. Ten years is a long time to work with one person and I have always found her patient, clear headed and wise. I am particularly grateful for her help in constructing a British social policy context for my findings. I would also like to thank Gill Hinson, Pat Hattersley-Smith, Esther Shafer and the members of the Women's Workshop on Qualitative Family and Household Research for their stimulation and support. The actual presentation owes much to Janice Harrison.

I thank my husband, Christopher, for his support, availability and belief in me. I thank Edward and Liz, my children, for their patience and understanding with my absentmindedness when pursuing such a long term project.

Lastly, I am enormously grateful to the eleven couples and five single people who shared their lives so generously with me.

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CHAPTER I THE IMPACT OF HEARING IMPAIRMENT ON THE COUPLE, THE FAMILY, AND THE SOCIAL NETWORK

INTRODUCTION

The aim of this study is to discover the challenges and the problems in marriages when one partner has a hearing impairment and the other hears normally. Since a marriage cannot be seen merely in terms of a relationship between the two people involved, but must be set in the context of wider family and neighbourhood relationships, the impact of hearing impairment on the inter-relationships between the couple and wider networks is a crucial aspect of this study.[1]

Such a study helps to fill an important gap in our knowledge. Looking at the broader field of social policy, Parker[2] acknowledges that despite a burgeoning of research on disability, marriage and family life, studies of marriage and disability are still rare, although the disability literature does contain some reference to the experience of married people[3] as well as personal accounts.[4]

The dearth of research in this area may be related to the interests and foci of different academic disciplines. The social policy literature has attempted to map the impact of various disabilities on people, specifically the deprivations caused by society.[5] Only after the deprivations have been made explicit, is it then possible to begin to look at their impact on relationships specifically the psychosocial dimension.

The feminist literature has also tended to ignore the relational processes within families by focusing on women's caring role in families.[6] Although a broader and more varied focus is being explored,[7] to date little interest has been shown in couples or in seeing this caring process as a mutual endeavour.

Psychologists, sociologists, social psychologists and child health experts have been interested in families and disability, but more from the perspective of the welfare of the children rather than their parents.[8] However, there have been exceptions, for example in social policy,[9] social psychology,[10] and in applied family and child studies. [11]

The study of the implications of hearing impairment on the family might also be thought to be of concern to the Church. In the ageing population, three quarters of the 7.5 million adults in the UK judged to have an acquired hearing loss, are over sixty years of age. However, in the 150 page report published by the Social Policy Committee of the Board of Social Responsibility of the Church of England, there is no mention of hearing loss. [12]

Moreover contemporary British research in the field of deafness itself is in its infancy.[13] Much of what has been done has focused on the prelingually profoundly deaf.[14] While this group now has a higher profile, people with acquired hearing loss continue to be neglected and notoriously to suffer from long term identity confusion caused by not knowing where they belong.[15] This is all the more puzzling as the numbers of people with acquired hearing loss greatly outstrip the number of prelingually deaf. For example in Great Britain, for every one prelingually deaf person, there are approximately 150 people who have acquired hearing loss.

Recent estimates suggest that this group will become even larger due to the growth of the numbers of elderly people in the population and the increase of NIHL (noise induced hearing loss). The National Acoustics laboratory of Australia has predicted that 78% of women and 25% of men will be hearing impaired by the year 2015 as a partial result of NIHL.[16]

The specific contribution of the present study is to focus on acquired hearing impairment within the marriage and family relationship. Initially a working hypothesis was developed that suggested that couples who contained a hearing impairment within their marriage needed to assess how it was affecting the quality

of couple and family relational processes. Furthermore, if this was not done regularly throughout the life cycle, it was predicted that familial processes would deteriorate in quality or not develop appropriately. Two crucial medical factors in the working hypothesis were the degree of hearing impairment experienced and the age of onset.

For this hypothesis to be tested, the method devised by Elizabeth Bott,[17] whose study of Family and Social Networks most nearly approximated to the type of research required, was adopted with certain adaptations. In using her approach along with other theoretical material, it has been possible to produce an ethnographic study which illuminates the interaction between peoples' psychosocial experiences and the medical and audiological nature of hearing impairment.

The small numbers and intensive interviewing involved provided an opportunity to establish the psychosocial factors which can modify or exacerbate the impact of hearing impairment on relationships. Such knowledge is intended to help clinicians[18] and researchers[19] to have a more profound picture of the lives of hearing impaired people that incorporates both positive and negative dimensions; and helps to lessen the likelihood that they will project their own negative fantasies on to their patients, clients, and respondents.[20]

With this purpose in mind, the plan of the thesis was established.

CHAPTER II THE METHODOLOGY

The focus of this chapter is on methodological issues, in particular the anthropological approach devised from the work of Elizabeth Bott, ways of looking at marriage, and the nature of interviewing.

CHAPTER III: ACQUIRED HEARING LOSS, A MEDICAL, AUDIOLOGICAL AND PSYCHOSOCIAL PERSPECTIVE

In this chapter the nature of acquired hearing loss is explored from a medical and psychosocial viewpoint. The relationship between hearing loss and other disabilities is analysed.

CHAPTER IV AN INTRODUCTION TO RELATIONAL PROCESSES AND INTIMATE RELATIONSHIPS

An investigation is made of contemporary marriage in this chapter and the development of relational processes is explored, focusing on issues of communication and intimacy.

CHAPTER V THE NATURE OF HEARING IMPAIRMENT: MEDICAL AND PSYCHOSOCIAL FACTORS AND REHABILITATION STRATEGIES

The focus of this chapter is on nature of the hearing impairment discovered, from both a medical and psychosocial viewpoint. Rehabilitation strategies are investigated.

CHAPTER VI: COMMUNICATION STRATEGIES

In this chapter, we discuss the management of communication for hearing impaired people particularly the nature of lipreading, focusing on the impact of stress, gender, and strategies to facilitate communication.

CHAPTER VII: THE PERCEPTION OF THE IMPACT OF HEARING IMPAIRMENT ON THE DEVELOPMENT OF COUPLE RELATIONSHIPS WHEN ONE PARTNER HAS A SEVERE/PROFOUND HEARING LOSS

The nature of the relationships studied is analysed in this chapter. Discussion centres on issues of mate selection, perception of deafness, and the development of social networks.

CHAPTER VIII THE PERCEPTION OF THE IMPACT OF HEARING IMPAIRMENT ON THE COUPLE DURING THEIR CONTINUING RELATIONSHIP

Here the focus continues on the couple relationship as it grows and develops, in particular how autonomy and intimacy are negotiated. There is also a discussion of marriage breakdown.

CHAPTER IX THE IMPACT OF HEARING IMPAIRMENT ON THE CHILD, THE FAMILY LIFE CYCLE, AND ROLES

The family is the focus of this chapter especially children's responses to having one parent who is hearing impaired. This is explored within the framework of the Family Life Cycle.

CHAPTER X THE IMPACT OF HEARING IMPAIRMENT ON THE SOCIAL NETWORK: KINSHIP

Here the formation of social networks is explored particularly within the wider kin group as a strategic response to the social isolation which can result from hearing impairment.

CHAPTER XI THE IMPACT OF HEARING IMPAIRMENT ON THE SOCIAL NETWORK: FRIENDSHIPS, PROFESSIONALS AND RELIGIOUS INVOLVEMENT

The investigation into networks is continued in this chapter focusing on Unger and Powell's[21] three levels of social support network formation for families where there is a disability.

CHAPTER XII THE SURVIVING PARTNER DURING AND AFTER BEREAVEMENT

There is a discussion here of the consequences of bereavement for a widow and a widower when both also have a hearing loss.

CHAPTER XIII REHABILITATION: A FORMAL AND INFORMAL PROCESS

The focus of this chapter shifts to the rehabilitation process both formally (with a detailed discussion of the role of hearing therapists), and informally by families, and through the personal initiatives of the hearing impaired people themselves.

CHAPTER XIV AN OVERVIEW OF THE SHARED PERCEPTIONS OF HEARING IMPAIRMENT WITHIN THE COUPLE RELATIONSHIP

Six charts analyse the major thesis findings in the penultimate chapter as they relate to the couples' shared perceptions of 'deafness as a difference' within their relationship.

CHAPTER XV CONCLUSION

The limitations of the study are discussed followed by an exploration of the impact of hearing loss on intimacy and the developing idea of the 'quality factor'. The management of hearing impairment and children, evolving conceptions of care, and 'rehabilitation worth' are also discussed specifically in the context of culture. Some assumptions and labels in the Deaf field are challenged along with a final summary of social policy recommendations and suggestions for further research.

Endnotes and Bibliography

Appendix including Profiles of Couples

NOTES AND REFERENCES:

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[1] The term 'hearing impairment' has been used to include all people with any degree of hearing loss from slight to profound. Despite certain people disliking the use of this term, hearing impairment is used descriptively in the current thesis because 1) no more appropriate term has presented itself and 2) it represents the comprehensive range of the people's hearing loss who took part in this study. These people must be seen as being neither totally deaf or totally hearing, if not in the physical sense, certainly in the psychological one. Also see Clarke, D. (1991) 'Ideologies of Marriage and Family Life' In D. Clark (ed.) Marriage Domestic Life and Social Change (London: Routledge) pp. 111-131.

[2] Parker, G. (1993) With This Body, Caring and Disability in Marriage (Buckingham: Open University Press) p. 10.

[3] ibid., p. 82.

[4] Kisor, H. (1990) Whats That Pig Outdoors (New York: Hill and Wang) p. 155.

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[21] Schilling, F., Gilchrist, L.D. and Schinke, S. P. (1984) 'Coping and Social Support in Families of Developmentally Disabled Children' In E. Earhart and M. Sporakowski (eds.) Family Relations Journal of Applied Family and Child Studies **33** (Blacksburg, Virginia: National Council on Family Relations) p. 49.

CHAPTER II METHODOLOGY

INTRODUCTION

The method which was used for the purpose of carrying out this study drew heavily on the anthropological/ethnographical approach developed by Elizabeth Bott.[1] There were a number of reasons for this. Since relatively little is known about the impact of hearing loss on marriage, it seemed imperative to use a qualitative exploratory method to mitigate at least some of the problems associated with the survey method such as its tendency to reinforce the pathological model of disability. It is important at the outset, however, to consider more generally the ethnographic method, before moving on to consider Bott's specific approach.

ETHNOGRAPHY

Ethnography is a research method which is frequently used to study unexplored social/psychological phenomena. The ethnographer participates overtly or covertly in peoples' daily lives for an extended period of time, watching what happens, listening to what is said, asking questions, in fact collecting whatever data is available to throw light on the issues with which they are concerned.

It was chosen for this study because of its flexibility and openness. It also has the ability to extract the meanings and subtle nuances[2] that give form and content to social processes such as marriage and the consequences of having a disability.[3] It is suggested that what ethnography lacks in reliability is more than made up for in validity.

The origins of modern ethnography are to be found in the late nineteenth century when anthropologists like Boas and Rivers studied the ways of life of a variety of tribes throughout the British Empire. Although they avoided learning the language of the tribes, they managed to formulate the ground rules for this type of exploratory research. E.E. Evans-Pritchard, Bronislau Malinowski, A.R. Radcliffe-Brown and Margaret Mead were all from this tradition.

There are, however, many scientists who do not trust 'soft methods' and believe them to be unscientific. Qualitative methods in general and ethnography specifically are seen to be 'too subjective' and not capable of providing a solid foundation for rigorous scientific analysis.[4] Other criticisms are that it is too expensive, laborious,[5] and that there could be ethical problems. The tensions created by this debate are ones which all social researchers feel between conceptions of science modelled on the practice of natural science on the one hand, and the ideas about the distinctiveness of the social world and how it should be studied on the other hand. Often this choice is presented as a preference between two conflicting paradigms.[6] While the names of the paradigms often differ, here they will be called 'positivism' and 'naturalism.' The former are seen to promote quantitative survey methods while the latter support ethnography as the central if not the only legitimate social research method. It is argued, however, that both positivism and naturalism are flawed in that they share the same fundamental misconception. They both maintain a sharp distinction between social science and its object. Researchers Hammersley and Atkinson[7] are convinced that it is an existential fact that we are part of the world we study and that we must recognise the reflexive character generally of social research.[8]

Before designing the methodology for this specific study, a search of the literature was made for possible models. While the focus was necessarily on the experience of hearing impaired people, this present study primarily explores hearing loss within the marriage relationship. This is because while working with couples as a social worker and marriage guidance (RELATE) counsellor, it had become evident what a force for health or illness the marital interaction of a couple could be and could become.[9] The importance of this dimension was reinforced by additional course work and supervision received at the Tavistock Institute of Marital Studies.

This interest in interviewing couples led to the marital and family therapy literature, and family sociology specifically the classic work by Elizabeth Bott: 'Family and Social Networks'.[10]

ELIZABETH BOTT: FAMILY AND SOCIAL NETWORK

Most students of the social sciences remember the Bott study not because of its methodology, but because of its findings connected with conjugal - role relationships. The main interest in Bott's work for this study lay in the use of repeated intensive interviewing. For those who have experienced social work or counselling training, the value of repetitive intensive interviewing is self evident.

Other studies come from a similar tradition.[11] Like Bott's study, they share a reliance on small samples, a willingness to engage in careful analysis of detailed accounts of married life, and the active promotion of depth interviewing as a reflexive sociological tool of inquiry.[12] It was decided to interview each couple ten times because this was roughly the average number of interviews completed by Bott and Rubin and because understanding a family takes time.

In following this tradition it is accepted that findings and interpretations from the study, regardless of their value qualitatively, cannot be regarded as samples of the general population in any statistical sense. Nevertheless, this does not mean that the selection of such a research group need be arbitrary and that the findings have no relevance outside those particular individuals. The fact that a group cannot technically be described as a representative sample does not automatically define it as unrepresentative.[13]

Another advantage of the Bott study is the way that different disciplines coalesce in the implementation of its methodology.[14] There are no apologies for a interdisciplinary team approach exemplified in the core staff of the study which consisted of two psycho-analysts, a social psychologist, and a social anthropologist.

Although it was not possible in the present study to replicate the interdisciplinary team approach of Bott, it was simulated to a certain extent. A range of skills was employed including those derived from marriage counselling and social work as well as personal experience of hearing impairment to identify the psychological as well as the social and policy dimensions of hearing impairment in couple relationships.

Because Bott's focus was on normal families,[15] it gave no help in finding out how disability, specifically the deafness of one partner in tandem with that of the researcher, would affect the developing methodology. The literature provides a number of examples where deaf researchers were used, the most helpful of which were the remarks of an American researcher in his study of the Deaf community in Washington DC metropolitan area. He wrote:

> "Deaf interviewers were superior to their hearing counterparts in obtaining information from Deaf respondents. Deaf interviewers had a lower refusal rate than did hearing interviewers. They were also more likely than hearing interviewers to make a positive impression on the deaf respondent such that the respondent would be willing to be interviewed again. These findings suggest that a hearing interviewer might obtain distorted information from deaf respondents".[16]

A more recent discussion was written by deafened researcher, Peter Woods.

> "Overall the presence of a deafened researcher is I believe not only beneficial but probably essential. In dealing with acquired hearing loss where the implications are to a large extent subjective and psychological...".[17]

From experience of having taken part in 150 intensive interviews with hearing impaired people when hearing impaired oneself, the researcher supports these views. However, there are also other important factors which help enhance the effectiveness of a hearing impaired researcher, including a reliable grasp of lipreading, previous interviewing skill, and an ability to notice and accurately interpret visual cues. It is also especially helpful to nurture an inner dialogue between the part of oneself which identifies with being hearing impaired and the part which identifies with being hearing to help achieve a balanced perspective.

Before looking at the development of the research design, it is important to look at some theoretical ways of looking at marriage which are relevant to this study.

WAYS OF LOOKING AT MARRIAGE: THE THEORETICAL PERSPECTIVE

Marriage and family may be seen as being in transition from institution to companionship.[18] More recent writings suggest that these two aspects of marriage when closely observed are in interplay with each other in some form of coexistence.[19] Because of such factors as the social emancipation of women, the emphasis on personal fulfilment, and the disassociation of sex from procreation through contraception, there has been a tendency to see marriage as a source of emotional fulfillment as well as a social duty. Consequently, couples appear to stay together because of a combination of external constraints coming from the public sphere and a relational component sometimes referred to as 'internal cohesion' found in the private sphere.[20]

SOCIOLOGICAL THEORY

If sufficient internal cohesion is the hallmark of today's flourishing marriage, it is important to look more deeply at the elements which contribute to its development. One way of doing this is to look at what different sociological schools suggest about marriage, to see if there is a theory that helps to interpret the evidence. For many years the functionalist approach[21] dominated sociological thinking about marriage. This body of theory tends to direct attention to the macro-social context rather than to the interaction between individuals. Functionalists have focused on sex-role divisions within marriage, and are best known for their distinction between the 'instrumental' role of the husband and the 'expressive role' of the wife. Married people are thought to be constrained in their adoption of marital roles by the expectations prevalent in society. This theory, however, does not adequately explain the changes taking place today in marriage. In other words, functionalists have failed to see the multi-faceted patterns of sex-role divisions in marriage and how roles, expectations, and relationships of husband and wife have been influenced by social change.

There is an opposing approach which emphasises conflict and change in contrast to consensus and stability. Although there are a variety of slightly differing schools of

thought within this approach, they all recognise three fundamental concepts: conflict, bargaining and power. The basic assumption is that without some means of avoidance or resolution, partners in a marriage will inevitably conflict with each other. There are two reasons for this. Firstly, it is thought that because partners are inevitably different, they will have different and incompatible values, norms or goals; and secondly, conflict is caused by the differential access of husband and wife to control over scarce and mutually valued resources eg., time, money and love. Although acknowledgement of conflict is very important,[22] there is much in the literature to suggest that this is not the foundation on which to build a whole theory of marriage.

Therefore, a third approach is required for a deeper understanding of 'internal cohesion'. This concept's basic assumptions can best be described as falling in to the symbolic-interactionalist school. Although the school itself defies description,[23] there are three basic tenets of the approach which are relevant to this study. Firstly, one cannot understand social behaviour without understanding an individual's own interpretation of objects, situations or the actions of others.[24] Thus marriage processes cannot be understood without an examination of how the participants themselves define what is taking place.[25] Secondly, symbolic interactionism holds that although the behaviour of husbands and wives is constrained by the norms or expectations of society, it is not determined by them. It believes both that individuals interpret norms and expectations differently, and that all couples have the opportunity to make choices about their marital roles, goals, and modes of operation. It is through the interaction of husband and wife that the special character and nature of each marriage emerges, as each person influences and reacts to the behaviour and attitudes of the other. Thirdly, implicit in the above, marriage is seen as a process, as a relationship which can develop or change as the couple continue to act and react to each other and to events and individuals in their external world.

FAMILY THERAPY THEORY

By exploring the term, 'process', it is possible to acquire a fuller understanding of the term 'internal cohesion'. Satir[26] suggests that the initial cohesive force in our Western culture is 'love', but that love alone can not sustain all the demands of married life.

This is partly because there are so many unrealistic mistaken ideas about love such as, love is 'sameness' or absence of conflict, and partly because there is another ingredient altogether which may be called 'the process' in the marriage. She describes this 'process' as being the way a couple work at nurturing their loving feelings; a couple's 'process' contains many complex dimensions. It can be revealed in such things as the quality of the couple's sex life and communication, their ability to negotiate decisions and delegate tasks, their constructive management of conflict. When this 'process' is highly developed, internal cohesion is also high.

The systems perspective, another related approach, incorporates an understanding of the processes described above. Galvin and Brommel[27] list eight assumptions which outline this approach. Four of the fundamental assumptions will be discussed here. First, in order to understand individuals fully, their functioning must be understood within the primary system of the family. Secondly, in committed relationships, cause and effect become interchangeable over time. Therefore, to understand what is happening, the present interaction rather than the past is the primary focus. Thirdly, human behaviour is seen as the result of many variables interacting together rather than the result of one cause. This shifts the focus from individual members' behaviour to the family as a whole with its interdependent relationships. This means family problems of any type must be viewed on many levels thus dismissing simplistic approaches. Lastly, the whole is greater than the sum of its parts whether those parts are individuals or sub - systems. Viewing the family as a system, highlights the importance of the need for accurate communication between parts of the system.

Although discussions of systems and 'process' are helpful in establishing a family therapeutic theoretical foundation for the study, the question still remains, 'What determines a couples' process?' A way forward with this question is to acquire some understanding of how the unconscious works within the marital relationship.

PSYCHOLOGICAL THEORY

Mattinson and Sinclair[28] claim that there are two theories which help them to understand couples' interaction on an unconscious level. The first is John Bowlby's theory of 'attachment and loss', and is predominately a theory of individual personality. The second is the theory of marital interaction as developed at the Tavistock Institute of Marital Studies (TIMS) in its clinical work with couples.

Bowlby believes that understanding the responses of children to the separation or loss of their mother figure is a reflection of the bond that ties them to her in the first place; for example, when young children are separated from their usual caregiver, they go through stages where they protest vigorously, despair of recovering her, and finally lose interest and become emotionally detached. Bowlby believes that this attachment has a biological base, and is to be found in primates of all species. He defines attachment behaviour as 'seeking and maintaining proximity to another individual'.[29] Throughout childhood the attachment figure remains important as a base from which to explore the outside world, and to which to retreat. Adolescence sees further change in attachment behaviour. This is a period of seeking and finding adult autonomy. The young person often displays extremes of behaviour; one moment fiercely independent, and the next clinging and uncertain. Then marriage gives the opportunity for reattachment to a specific figure, and legally sanctions attachment behaviour. Often attachment behaviour is heightened at times of crisis, rebuff, sickness, the birth of a child, or when prolonged separation is threatened. However, presuming the environment is not too frightening, and there is a degree of basic trust that help will be available when required, the attachment behaviour will continue at a relatively low level until old age.

Bowlby's theory of attachment and loss has been adopted for this study as it is likely to be useful for understanding some of the tensions and stress which the loss of hearing precipitates. It was hypothesised that attachment behaviour within a couple's relationship would become more pronounced and altered where one partner has a hearing impairment. There may be echoes of earlier developmental stages as testing goes on to see if the new vulnerability can be absorbed within the framework of the

existing relationship. Such behaviour as clinging, dependency, compulsive independence, and doubting may set up a vicious circle which upsets the couple's established equilibrium. If the relationship is to survive in a healthy way, a new equilibrium needs to be found based upon a reassessment of the needs of both partners.

Another psychological perspective on marriage is offered by marital interaction theory. This theory suggests that marriage is more than Bowlby's 'finding a suitable object of attachment'. TIMS puts forward two other psychological purposes for marriage: one is concerned with psychological development and the other is concerned with the avoidance of psychological pain.[30]

From the developmental point of view, the opportunity to reattach and therefore, to be in touch with feelings associated with attachment holds the promise of being able to make better what was felt to be wrong in the past, and to make partnership more satisfying than was dimly remembered from childhood. The likelihood of being able to do this is heightened by the unique combination of responsibilities of family life, and the opportunity to behave childishly within the intimacy of a sexual relationship.

Furthermore, the partners may choose each other as complements to express what they cannot express for themselves. Some of these different characteristics may be valued, and others may be feared; but if they can be handled within the current situation, and experienced as less destructive than previously, healing takes place.

It is thus possible to understand C.G. Jung's vision[31] of marriage as an 'emotional container'. Just as a young child needs to be contained and given a 'home base', so too may adults develop more of their fullness of nature if provided with an emotional container.

Counsellors often see marriage used defensively to ward off conscious and unconscious anxieties of both partners, and to prohibit development. This happens when these anxieties are shared so that both partners are locked in a 'straight jacket' relationship. The couple has a vested interest in trying to avoid particular situations which they feel might be disastrous. This may be so even when at first sight their ways

of handling their fears may be quite different. An example of this is the woman who clings to her husband while he appears to be completely unconcerned and detached. As these apparent opposite behaviours both reveal anxiety about dependence, it is likely that both have suffered greatly in the past from the loss of loved ones, and fearing that history will repeat itself, continue to have difficulty in trusting attachment figures.

The next question is how marital interaction theory can be applied to a marriage when one partner is hearing impaired. It is likely that defences will develop to ward off the reality of the deafness and its implications. TIMS defines 'defences' as the techniques the ego uses when the conscious mind is under greater strain than it can bear. Such strain may be caused by pain, anxiety or conflict. The whole notion of 'defences' owes more to Freud and classical psychoanalysts than to Bowlby. Freud suggests that the defences of repression, denial and splitting of the ego are often traced to experiences of loss. This could apply to the loss of hearing.

Of these three defences, 'splitting' is particularly important in our discussion of deafness and marriage as it may contribute to the 'denial' of the problem. The defence of 'splitting' may be described as a mechanism whereby, when a person has conflicting feelings about something such as a partner's deafness, either the positive or the negative feelings drop into the unconscious. This is believed to occur when the hearing partner has not fully accepted their partner's deafness. The hearing impaired partner then receives the unconscious message that they must keep anything negative connected with their hearing loss outside the marriage boundaries and true integration does not take place. This process will be discussed further in Chapter XIV.

Thus marriage, and more specifically marriage where one partner is hearing impaired may be viewed from a number of different theoretical perspectives. These perspectives are then made useful in the way in which they inform the interviewing process. It is now appropriate to return to the research design specifically to show how access was achieved and the nature of the sample.

ACCESS TO WHOM AND WHY?

Because there was no register from which a representative sample could be drawn, some other method was needed to locate people for this study. Two methods were eventually adopted. Burgess[32] calls them 'judgement' and 'opportunistic' sampling and 'snowball' sampling.

Judgement sampling refers to the process of selecting people for a study who possess certain criteria established by the researcher. In this case, eleven couples were chosen where one partner was hearing impaired. Later five hearing impaired single people were added to complete the study. It was hoped that the group of single people, whose partners had left them as a result of death, divorce or separation, would add additional perspective from the insights gained in looking back at their marriage.

Because each member of the 'singles' group represented half a couple, they were interviewed one half as many times. It was also possible to interview at least one child in every family. In the case of one elderly hearing impaired man, it was possible to interview both his children and grandchildren.

Another factor desired was that each couple/family should represent a distinct phase in the Family Life Cycle (FLC), a method established by Olson, McCubbin and Associates.[33] It was in this cross-sectional context that the twenty-eight children were interviewed with the FLC providing a structure for analysis. The FLC was chosen over the 'life course' approach[34] because it offers a strict chronological developmental analysis which was seen to be more appropriate for this specific exploratory study. Its use is in no way a denial of the unique variations which family life presents.

A variant of snowball sampling was also used. This approach involves using a small group of people who are asked to put the researcher in touch with their friends who are subsequently interviewed. Four couples found at the 1988 AGM of the National Association of Deafened People became the nucleus of the study. Other people were found through sponsors known to the researcher through her membership of certain organisations: the Committee for Staff and Students with Disabilities at the Institute of

Education University of London, the Women's Workshop on Qualitative Family and Household Research, and the Church of England. This situation confirmed Bott's experience[35] that personal sponsorship is most likely to lead to committed respondents.

THE SAMPLE

While some experts in the Deaf field would argue that a study sample should consist of either prelingually deaf people or people with acquired hearing loss, the researcher was interested in observing a group of people that represented a continuum. In other words the range rather than the degree of deafness was the important factor.

Although the eleven couples and five single people in the study had hearing impairment as a common factor, there was considerable variety in other social factors. This was seen to be appropriate in order to avoid the stereotypical view that hearing impaired people are a homogeneous group.

For example, of the 27 adults in the study, 11 could be considered members of social class I on the Registrar General's classification; nine of social class II, six of social class III , none of social class IV, and one of social class V. Also related to class was the fact that all but one of the 11 couples were dual career couples in the sense that both husband and wife had regular earnings.[36]

Not surprisingly class seemed closely connected with years of education. Eleven people had received a professional qualification and/or an advanced graduate education; six had received BAs and six had done some A levels and/or an additional diploma. Four people had received a secondary education or less. The small number who did not have general educational qualifications on a high level were in practice very articulate.

Ethnicity, religion, and gender were also social factors examined. The nationalities represented included English, Scottish, French, Nigerian and American. The religious affiliations represented were Anglican, Methodist, Presbyterian and Judaism. With respect to gender, of the sixteen hearing impaired people who took part in the study,

eight were men and eight were women, though half the women belonged to the single hearing impaired group among whom there was only one man.

There was also considerable variety among the couples with regard to degree of hearing impairment. Of the 16 hearing impaired people in the study, six were diagnosed by their audiologists using a pure tones test as having profound to total hearing losses; four people were diagnosed as being severely hearing impaired, three people had moderate to severe hearing losses, and three people were diagnosed as having mild to moderate losses. There were people in the study who were born deaf and/or acquired a form of deafness later in life. Different types of deafness were represented. Most of the sample had sensorineural losses, but one had a conductive loss specifically otosclerosis. The rapidity of loss varied: three hearing impaired partners had experienced sudden traumatic loss while the remaining 13 experienced their losses gradually.

In selecting couples, formal marriage was not considered an essential criterion though in the event, all but two were married. One couple had cohabited for ten years and referred to their relationship as being 'lovers'. A factor which was of more concern was the 'stability' perceived in the relationship.[37] Did the couple possess the equilibrium needed to withstand sustained involvement with an outside researcher along with a genuine interest in exploring the topics under discussion; or was there a certain fragility present that made the possibility of early withdrawal likely, for example a suspicious, hostile or prickly couple presentation.

THE INTERVIEWS

THE INITIAL EXPLORATORY INTERVIEW

This concern made it imperative from the outset to communicate the demanding nature of repeated intensive interviewing. An important aspect of establishing the trust required to sustain people's involvement in the interviewing process was an open discussion of the interviewer's own family history and hearing impairment.

Understandably the open ended nature of the initial questioning resulted in some anxiety, experienced also in Bott's study.[38] Therefore, guidelines for discussion were drawn up and presented to each couple at the initial exploratory interview. They were helpful to most although one couple refused to see them for fear they would inhibit rather than help the sharing process.

Also included in the interviewing process were marital exercises devised by the researcher from a guide for marriage enrichment.[39] While the original purpose of the exercises was to help couples improve their ability to communicate openly, solve problems, and manage conflict, their use in this study was to stimulate discussion in more intimate areas of married life. These were based on a 'developmental' framework.[40] One hearing partner at the beginning of the study found direct questions about sex to be 'rude' so this aspect of marriage was not asked about explicitly. Instead there were questions about romance and decision making which some couples used to open up discussion about aspects of their sexual relationship. It was thought that this indirect approach was necessary because unlike the disabled people interviewed by Parker,[41] the disability of deafness does not block physical contact in an explicit way; and therefore, was not seen to be obviously problematic.

There was also a special discussion of the couples' communication patterns with a focus on how they might fall short. These exercises in self assessment were an alternative to direct questioning and provided additional perspectives on the marriage.

NATURE OF INTERVIEWS

Initially the decision was made to interview both husband and wife exploring deeper issues of conflict and differences, using listening techniques learnt in RELATE counselling training,[42] and also known to social researchers.[43] They provide an atmosphere in which different issues can be safely explored. Also structured into the sessions from the beginning were expectations that couples would be interviewed together and separately. The reason for this approach was that the interviewing needed to reflect the idea that marriages are composed of three parts: the individuality of the husband, the individuality of the wife and their joint relationship. Added to this

explanation was the delicate nature of the actual material under discussion, and the belief that some of it might be more accurately shared during a private session. When the time came somewhere around the fifth interview to separate couples, they seemed happy to cooperate although there were some times flip remarks like, "Is it safe?" and "I'll listen through the key hole". An attempt was made to lessen the tension about separate interviews by having them on the same evening.[44] Some couples shared the content of their individual interviews with each other, while others did not.

All the interviews took place in the people's homes. The exact positioning of the interviews was important since effective communication was best when sitting relatively close together in full view of each other's faces. Experience suggested that the most suitable place was the kitchen or dining room table. Here there was room to put down tape recorder and note pad. A second best was the living room with chairs pulled forward in a semi-circle. Wood argues that an office interview is preferable over one in the home since there are usually fewer distractions.[45] However, an office may in fact have just as many disruptions as a home without the additional insights gained from observing people in their own environment.

THE AGREEMENT FORM AND FILE

It was important to make the interviews as egalitarian as possible to avoid distortion and 'interviewer bias'.[46] One method to help this process was found by devising an Agreement Form. The people in the study were shown the form and asked to sign it if they wished. The form discussed confidentiality, procedures about publication of findings, expectations of individual interviews, and premature withdrawal from the study. Most of the couples signed it at the second session when they began to understand the nature of the study. Others preferred to wait until the interviewing was finished before signing. One couple, both members of the legal profession, rewrote parts of it and their suggestions were incorporated. Some couples expressed the concern that the Agreement Form was making everything too formal. Others understood the practical and ethical value of it in case some aspect of the study was misunderstood or misheard. The provision of a file for the papers required. helped to ensure that the exercise was taken seriously by everyone involved.

CONTINUING INTERVIEWS

The correct pacing of interviews with each couple was important to establish. Because there was so much variation, it took a little time to find the most appropriate speed which included both hearing and hearing impaired partners and the hearing impaired researcher.

Couples were also asked how they felt about the gender[47] and the disability balance in the interview. For example men were asked how they felt talking with two women and the hearing partners were asked how they felt talking to two hearing impaired people.

The length of the interview was another point negotiated. As the researcher travelled by public transport, some interviews ended abruptly since there was a train to catch. Some couples complained that one hour was not long enough since they were just 'warming up'. When this happened, the session could sometimes be rearranged to one and a half hours. With the vulnerability and diversity present, it seemed essential not to go over the time limit, and also to honour the psychological defences in use.

The number of interviews was not directly contested. Once the interviews were established, there seemed a gradual shift from 'public accounts' to 'private accounts'.[48] Only the first couple withdrew prematurely. The reason given was that the hearing impaired wife had taken on responsibilities which she perceived as being incompatible with her role as respondent in the study.

RESEARCH TOOLS

The research literature suggests tape recorders are a 'mixed blessing'. In this study they and the resulting typed transcripts were vital. Apart from providing a full record of the interviews, and a source from which illustrative material could be drawn, as time went on, they also aided recall and that which had not been heard or was considered inconsequential at the first reading. This helped to develop a more sensitive and accurate interviewing technique.

Five secretaries worked on the transcripts. The work of the secretaries was partly paid for from a grant received from the LSE graduate school. Hand notes of every session were also taken and typed up afterwards. They acted as a more immediate reminder of what had taken place. They also showed more quickly what had been covered, and in what direction the interviews were going.

Initially it was hoped that a number of interviews would be videoed. However, it soon became apparent that the size of the equipment and the distances involved made this plan impractical. Fortunately, it was possible to video one couple twice and this has since been used for demonstration purposes.

British Sign Language was not learned since as it emerged, it was not that relevant for this specific study as only one couple used it on a regular basis. They were surprised at the researcher's lack of skill in BSL and would probably have withdrawn at that point except for the fact that their sponsor had given the researcher an excellent recommendation.

ETHICS

The literature suggests that qualitative research with families is particularly vulnerable to problems of ethics.[49] This is because it is not possible to apply the principle of 'informed consent' clearly. This principle assumes that a researcher understands and can assess all the risks and possible benefits associated with the project because they see the research in its totality. However, qualitative family research is conducted more as an ad hoc process whereby the researchers usually do not know everything they are looking for when they start out and structure their study to some extent as they go along.[50] Thus it is nearly impossible in a qualitative study for a subject to be completely informed about the nature of the research at the outset of the project.

Couples appeared to participate in the study for different reasons. A number of couples approached it as a way to evaluate themselves as Bott[51] also found. They were aware of a certain level of risk, and managed to keep the balance between over and under risking in what they revealed. Others were a little more anxious and expressed concern

that some of the questions asked might spoil something special which they had as a family or as a couple.

Another area which has not been properly developed is a statement of ethical practice for interviewing children. Although codes have been devised for psychological[52] and medical research (Department of Health) for interviewing children, similar codes have not been generally drawn up for social research. The parents of the younger children in this study wished to know ahead of time what topics would be discussed. However, they were happy to allow the responses of their children to remain confidential. Children ten and under were interviewed with their parents present.

SUMMARY

The main argument of this chapter is for the use of an anthropological/ethnographic approach [53] when examining the impact of hearing impairment on family life. Although the survey approach has previously been useful in conveying many of the problems experienced by hearing impaired people, ethnography is a more satisfactory approach because it is better able to reveal the multi-faceted aspect of the problem.

It is also argued that a disciplined 'dual focus' be maintained when interviewing hearing impaired people about their lives. By focusing on both 'deafness' and 'family', both positive and negative aspects of the problem are revealed resulting in the emergence of a more balanced picture of hearing impaired people.

A subsidiary argument is that hearing impaired researchers are useful in this process provided they enter the field well prepared and supported. Although it might be argued that this would hold true for the execution of any successful research and that stress is inevitable part of the research process, hearing impaired researchers are likely to experience additional problems. If some of these problems are discussed before entering the field, the work is more likely to be executed with competence and ease.

A number of perspectives from different fields are outlined as being useful in this study. The systems approach used in family therapy, psychoanalytic insights from

marital therapy, symbolic interactionism from sociology, and the family life cycle from developmental psychology all facilitate insight. The latter was particularly useful when analysing the remarks of the 28 children in the study.

Lastly the point is made that this study is well founded despite/because of its small size in that the sample is representative of a very large range of people medically and developmentally. Hearing impaired people in every stage in the life cycle are included. The people came from a wide range in terms of background and social factors, for example class, education, ethnicity and religion which makes for more interesting comparisons and succeeds in breaking a way from the negative stereotype of the depressed isolated and helpless hearing impaired person of past studies.

The discussion now moves to consider the dual focus of this study which will be introduced in Chapters III and IV.

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CHAPTER III ACQUIRED HEARING LOSS: A MEDICAL/AUDIOLOGICAL AND PSYCHOSOCIAL PERSPECTIVE

INTRODUCTION

The major concern of this thesis is the psychosocial implications of acquired hearing loss. However, before considering this matter, it is necessary to examine relevant medical and audiological factors. This chapter examines the nature of acquired hearing loss, specifically its prevalence and makes an important distinction between prelingual deafness and acquired hearing loss. It continues by considering the two factors believed to have the most impact on adjustment: the time of onset and the degree of loss. Then follows a discussion of other salient factors such as types of hearing loss, its aetiology, rapidity, and the nature of residual hearing. With this foundation, the discussion shifts to examining the psychosocial implications of acquired hearing loss. The literature is reviewed specifically in connection with mental health issues, personal identity and social networks, group identity, bereavement stages, stress, and stigma. We will begin with a definition of acquired hearing loss.

THE NATURE OF ACQUIRED HEARING LOSS OR LATE ONSET DEAFNESS. MEDICAL AND AUDIOLOGICAL FACTORS

Broadly speaking, acquired and/or late onset deafness is hearing impairment which occurs later in life. 'Later', however, has no standard definition. Furth defines 'late' onset deafness as developing as early as the years of language acquisition.[1] Others see it as occurring at or later than puberty.[2] The second definition suffices in this study.

Researchers and clinicians point to a) time of onset and b) degree of deafness as the most significant factor in predicting the level of adjustment.[3] Other significant descriptive factors are: c) prevalence; d) type of loss; e) its rapidity, and f) the

nature of residual hearing. The discussion will begin with prevalence so as to provide a statistical context and some hard evidence.

PREVALENCE

Hearing impaired people do not form a homogeneous group. They differ in many ways. Research suggests that 17% of the adult population in Great Britain have a hearing impairment of 25 decibels or more.[4] This population may be further subdivided between prelingually Deaf people and those with an acquired hearing loss. It has been estimated that there are 25,000 profoundly prelingually Deaf people of all ages living in Great Britain. In contrast, there are approximately ten million people with acquired hearing loss in the UK.[5] The majority of these people are over the age of sixty. At the other end of the age range, the number of children born with some degree of deafness is approximately three in every one thousand births. In addition to this, many children experience fluctuating hearing problems associated with middle ear infection ("glue ear") during childhood.

The literature indicates that previous scholars often confused individuals who were prelingually Deaf with the much larger population of deafened adults.[6] Since eleven out of the sixteen hearing impaired people interviewed in this study acquired their hearing losses after the age of 25, the primary focus of this study will be those with acquired or late-onset hearing loss.

Prevalence may also be measured by considering communication strategies used. The number of people with National Health Service hearing aids is now estimated as approaching two million; and that at least half a million own commercial hearing aids (some of whom will also have NHS aids). Since there are four million potential hearing aid users in the UK, there is still a considerable gap between the number who have hearing aids and the number who would be likely to benefit from them. Statistics on NHS provision indicate that there is higher uptake of hearing aids among the more severely affected end of the potential population.

Researchers estimate that 70,000 to 80,000 people communicate manually in the UK. There are no statistics available concerning the number of people who use lipreading as a communication strategy.[7]

TIME OF ONSET

Time of onset is significant because individuals whose hearing loss occurs before language has developed will have very different life experiences and present themselves in quite a different manner from those whose hearing loss has occurred subsequently in childhood, adolescence, maturity or old age.[8] It is also suggested that both an individual's current age and the age of onset will give an indication of the meaning of hearing loss to the individual. If the loss is first suffered at a stage of life when it was felt to be untimely or exceptional, it is experienced in a more threatening manner than the same disorder (such as presbycusis) encountered at a later stage such as between the ages of sixty and seventy. At this time it is seen as conventional and part of the ageing process.[9]

THE DEGREE OF DEAFNESS OR THE SEVERITY OF LOSS

The degree of deafness is also seen to be very important as it indicates how well a person can understand human speech. Hearing loss is usually measured in terms of the quietest sounds a person can hear using a decibel scale and a pure tones' test. There are various ways of describing what a given loss means in practice.

The following is based on the American Committee on Conservation of Hearing:

26-40 dB mild - Difficulty only with faint speech

41-55 dB moderate - Frequent difficulty with normal speech

56-70 dB moderate - Frequent difficulty with loud speech

71-90 dB severe - Understands only shouted or amplified speech

over 90db profound - Usually cannot understand even amplified speech.

These categories are to be seen as coarse descriptions of very complex issues.[10] They also may be used to understand roughly the range of loss found in the sixteen hearing impaired people in this study. However, it is very important not to use these classifications to draw any fixed conclusions since two individuals with the same degree and patterning of hearing loss may differ markedly in actual speech discrimination ability, in cultural identification, and overall adjustment.[11] Nevertheless, some very rough guidelines are given. Assuming that the loss is equal for both ears, with a mild loss, the person begins to strain to hear, may raise the volume of the television a bit and occasionally ask for repetition and give wrong answers. If the person has a moderate loss, there is a need for frequent repetition, much louder volume of television, frequent wrong answers and misunderstood words in group conversations, and noticeable fatigue from listening intently. A severe loss is evident to everyone and usually requires a hearing aid. The person with a profound loss hears only very loud sounds if anything.

From the degree of loss, it is now appropriate to focus on the type of hearing loss.

TWO TYPES OF HEARING LOSS

There are two main types of hearing loss: conductive and sensorineural. Very briefly anything which inhibits the passage of sound from its source to the inner ear results in a conductive loss.[12] Generally a conductive loss is not considered as serious as other types because it can be treated medically and surgically. However, positive medical interventions may occasionally precipitate psychological or marital difficulties.[13] This is because it is likely that a certain relational equilibrium was reached before the operation, and a new one will have to be re-established afterwards. Discussion of specific marital issues connected with adjustment to hearing loss are found in the following chapters.

One of the most common types of conductive hearing loss to be treated surgically is otosclerosis. This is an inherited condition and genetic counselling is recommended for family members. It affects the bony capsule surrounding the inner ear. As the

disease gradually destroys the healthy bone, a soft highly vascular bone develops. The result of this process is that the stapes (stirrup bone) become stuck in the oval window. In this position the stapes can no longer vibrate and a conductive hearing loss occurs.[14] Otosclerosis and other conductive losses respond well to the use of a hearing aid which means that if the inner ear is normal, there is usually little difficulty with distortion.

Conversely, the use of hearing aids and other assisting devices, providing mere amplification or refinement of sound are insufficient to improve a sensorneural loss because of the distortion which takes place. With the exception of the cochlear implant operation, there is still no effective medical or surgical treatment which may be offered to people with sensorineural loss. It is for this reason that learning the skill of lip reading is an essential rehabilitation strategy.

Thus the seriousness of this type of hearing loss results from its nearly imperceptible onset and insidious progress which medical intervention at this time is unable to correct.[15] However, this fact has also challenged researchers; and, as a result of continual experiments with birds and rats, insights into the nature and regeneration of sensory hair cells are emerging.[16]

The exact aetiology of sensorineural hearing loss is varied and complex. Hearing impairment may be caused by some of the following aetiological factors: noise, experience of ototoxic drugs, the ageing process, genetic inheritance, and infections. It is the high fever caused by the later, for example in scarlet fever, diphtheria and meningitis, which is likely to damage the hair cells. However, without question, the commonest cause of a sensorineural hearing impairment is the 'wear and tear' of old age. This occurrence results in a loss of acuity in the mechanisms of the inner ear resulting in a condition which resembles sensorineural loss generally.[17] This type of hearing loss is bilateral, symmetrical and is known as presbycusis. It is now believed to have a major genetic component.[18]

One question which still remains is why hearing loss is more pronounced in some people(s) than in others. It is thought that the rapidity and degree of impairment may be influenced by the specific lifetime of the ear particularly by exposure to noise.[19] Evidence found by Rosen suggests that members of primitive societies where there is little noise pollution, have sharper hearing than their counterparts in industrial societies.[20] A similar parallel may be found in understanding why older women experience less hearing loss than older men. Although this fact may be changing along with women's roles generally, in the past they have encountered less superfluous noise in their lives since excessive noise levels in the home are usually easier to control than outside. Alternatively, the most significant factor here could be the absence of stress. Rosen found evidence for this also in his studies of elderly members of primitive tribes. They were found to have less heart disease as well as more acute hearing.

OTHER FACTORS

There are other audiological factors to be considered when assessing the impact of sensorineural hearing impairment on adjustment. Firstly, there is the rapidity of hearing loss. Reactions to hearing impairment vary according to whether its onset is sudden or gradual. When people are suddenly deafened, personal accounts suggest there are likely to be sharp pangs of grief in contrast to a more diffuse sense of mourning that accompanies a gradual loss.[21] This question of the rapidity of loss may also explain why there is often some ambiguity in respondent's reported time of onset, for example, many losses are often gradual and consequently long periods of time elapse before they are noticed and considered problematic.

Another factor is the specific nature of the residual hearing. This is determined by a number of sub-factors such as aetiology, rapidity, and type of hearing loss. For example, some people may have residual hearing in the higher frequencies, the lower frequencies, or both. Depending on the frequencies and patterning of the remaining hearing, it is usually possible to provide a hearing aid for sounds in the speech range; or failing this, for grosser environmental sounds. In recent years, the

cochlear implant operation has provided deafened people with a means of hearing some of these sounds.

There are a number of complications or side effects associated with residual hearing. Tinnitus, recruitment and vertigo are the most common. Tinnitus is a condition which produces unremitting or recurrent ringing in the ears of greater or lesser intensity with no apparent outside stimulus. While it is most often associated with sensorineural loss, it has been known to accompany conductive hearing loss and normal hearing.[22] Recent reports suggest that 50% of the people who complain of a hearing loss to their doctors in the U.K., also complain of tinnitus.[23] At present there is no cure although some people find masking devices, positive thought and relaxation techniques useful. The phenomenon of recruitment means that a relatively slight increase in the intensity of sound results in a disproportionate increase in the sensation of loudness.[24] This may cause the dynamic range of hearing to lessen. Cases have been reported where fairly loud sounds which cause little discomfort to hearing people cause stress and pain to those with a hearing impairment.[25] This disorder is thought to be caused by sensory cell damage. Vertigo is a complication most often associated with Meniere's disease. The symptoms include repeated sudden attacks of whirling vertigo, accompanied by nausea and vomiting. These episodes may last anytime from ten minutes to eight hours. Tinnitus may also accompany this condition.[26] These specific complications have been explored since they were experienced by the people in this study.

PSYCHOSOCIAL IMPLICATIONS

An acquired hearing impairment is more than likely to disrupt relationships since the ability to hear is so central to relational processes. It is evident that having a hearing impairment is not merely about the physical process of not hearing, nor is it just about the frustrations which are felt in losing access to a certain level of information and conversation.[27] Seen from this psychosocial perspective, the problem is much deeper and more encompassing in that it strikes at the heart of all social relationships in both the private and public sphere. With limited rehabilitation

and organisational support, or social awareness, people with declining hearing in the UK have had to cope with out help at work, at home, and in social settings. This has been documented vividly in personal accounts by clinicians and researchers.

This chapter follows the preceding one in endorsing the systems perspective.[28] People are considered as part of an overall context, not simply as individuals with a personal problem. Individuals do not exist without a context.[29] Therefore, it is argued that a communication problem such as deafness belongs to the individual, but also and equally belongs to the family, social networks, and to the whole of society.

MENTAL HEALTH ISSUES

There are also implications in the systems approach for looking at the mental health of people with acquired hearing loss. Researchers and clinicians suggest that negative behavioural and emotional characteristics presented by many deaf and hard of hearing clients have come about, are supported, and are reified as a function of the interaction within and between systems. Although it is not always the case, this statement implies that the majority of mental health problems of deaf and hearing impaired people are rooted in context, not individual pathology. Harvey argues that such problems are often the result of interactions with people who have generally negative attitudes about deafness and hearing impairment, although these attitudes may be disguised as concern.[30]

Research has drawn attention to the tendency of personal accounts to emphasise the traumatic aspects of hearing loss.[31] The affected person is seen as anxious, withdrawn, suspicious, hostile and lonely.[32] This stereotype has repeatedly been reinforced by other studies which attempt to find a link between hearing loss and psychological disturbance.[33] Although in no way questioning the importance of these early studies, recent research has sought to question the comprehensiveness of such evidence.

In the past decade as deafness has begun to be depathologised, more hopeful personal accounts have been written.[34] These accounts show that it is possible for a hearing impaired person not only to achieve a tenable position in the hearing world, but also to be acknowledged as a public figure. In addition, the more intimate details of family life and friendship development have emerged. Alongside these autobiographical accounts, a new generation of research has attempted to overcome some of the past sampling and methodological difficulties.[35] However, with very few exceptions, they have tended to reinforce the model of deafness as a pathological state. For example, Thomas discovered that "although severe hearing loss was not associated with a very high level of psychological disturbance as in the first study, hearing-impaired adults were still nearly four times more likely to be psychologically disturbed than were normal people".[36] The psychological disorders existed at the 'psychoneurotics' level and did not result in obvious abnormal behaviour.

Wax argues that such pathological labels must be viewed with suspicion since hearing impaired people are measured against mainstream 'hearing' norms and standards.[37] A more effective paradigm is to examine psychological and mental health norms so as to perceive what constitutes appropriate cognitive, affective, and behavioural standards and norms for Deaf and hearing impaired people. Sussman[38] proceeds by identifying 'overcoming skills' or key characteristics of the psychologically healthy deaf person. They include the following:

a) positive psychological acceptance of hearing impairment
b) positive self concept/self esteem
c) ability to cope with negative and/or patronising attitudes
d) assertiveness
e) ability to place speech ability in perspective
f) positive attitudes toward communication devices
g) socialization with other hearing-impaired people
h) ability to survive 'misguidances'
i) philosophical and unhostile sense of humour

j) "gemeinschafftegefuhl" (joy of life).

Although this list is primarily developed in relation to members of the Deaf community, it also is relevant for people with acquired hearing loss.

PERSONAL IDENTITY AND SOCIAL NETWORKS

The concept of 'personal identities' is used here as a way of exploring how individual differences affect the way people with acquired hearing loss respond to the constraints felt. Erikson defines personal identity as "the ability to express oneself as something that has continuity and sameness, and to act accordingly".[39] He sees adolescence as the major time for formulating identity (personal, sexual, occupational and ideological) in preparation for adult life. Other times of 'identity crisis' occur throughout life especially at significant transition points such as marriage, divorce, birth of children, geographical relocation, changes of occupation or status, redundancy, retirement and bereavement.

Research suggests that identity disruption is most strongly felt in the specific areas of social communication and body image.[40] Since most people are socialised in the dominant hearing culture, the deafened person is most likely to have absorbed the view that hearing loss is a physical disability with connotations of pathology and stigma. Thus it is understandable that Levine detects trauma (an upset in psychic balance) in the response of those recently afflicted as opposed to the relatively contented outlook of those born deaf.[41] While prelingually Deaf people have in most cases developed in the company of their Deaf associates, those with acquired hearing loss find themselves isolated without a congenial 'reference group'.[42] Some researchers go so far as to suggest that the family,[43] or the partner specifically,[44] may then become a substitute for the lost 'social worlds'.

GROUP IDENTITY

Before exploring further what those with acquired hearing loss lack, it is appropriate to look briefly at how sociologists view 'communities' and how prelingually Deaf people and their theoreticians have adapted this view.

Most sociologists are in basic agreement that communities consist of people in "social interaction within a geographical area and having one or more additional common ties".[45] It is felt that this definition broadly characterises Deaf communities in the USA. Generally physical proximity is lacking with certain exceptions such as residential schools, Gallaudet College, and the Columbus Colony housing project in Westerville, Ohio. The emphasis is primarily on common characteristics, experiences, language, type of education, needs, interests, and self identification.[46] Another perspective sees the Deaf community also as an ethnic minority group.[47]

There is certainly some disagreement in the literature about whether or not there is a Deaf community; and if so, how unified it really is. Padden and Humphries[48] choose to emphasise its unity by following precedent in using lower case 'deaf' when referring to the audiological condition of not hearing, and the upper case 'Deaf' when referring to a particular group of deaf people who share a language (for example, American Sign Language),[49] and a culture.[50] They argue that American and Canadian members inherit their sign language, use it as a primary means of communication between themselves, and hold a set of beliefs about themselves in relation to the larger society.

Others see this notion as simplistic and naive. They emphasise the community's multi-faceted and dynamic nature and point to the many diverse groups with special interests for example, gay and straight; old and young; black and white; professional and working class, who are essentially uncommitted and may come and go from the community.[51] Or they emphasise how working life brings about integration, an achievement not to be diminished just because community members

choose to use language in leisure hours which they feel to be more relaxing.[52] It is pointed out that not all members of the Deaf community are prelingually deaf as is apparent from their clear and natural speech. Onset may occur in their teens while others acknowledge their new identification later in life. Another factor sometimes completely overlooked is the enormous ambivalence which many Deaf people feel towards their disability and towards their community. This ambivalence centres around three areas: l) who is and who is not a member of the Deaf community? 2) do they accept their impairment or do they wish they were hearing? 3) conflicting emotions that members feel about speaking and Signing.[53]

Participation in the life of the Deaf community has been briefly described here since it is one of the 'lifestyle choices' for people who lose their hearing in adult life. 'Lifestyle' in this context is referring to the 'enduring patterns of living, loving and working in the world'.[54] One person in the study chose the Deaf Community as his lifestyle choice, but after he married his hearing wife, they became 'bicultural'.

Researchers perceive a total of four possible lifestyle choices. Those who choose the Deaf community are described as maintaining a lifestyle which segregates them partially as a social minority group from the larger hearing world.[55] The hard of hearing, the second group, are usually 'mainstreamed' into the larger hearing world and tend to become part of the same cultural framework as most service providers. With two exceptions, this was the 'life style' chosen by all the people in this study. The third group consists of deaf and hard of hearing people who are 'biculturals' and can move between the Deaf culture and mainstream society; these people tend to be bilingual and have a broad range of social skills learned in both worlds. A final group could be considered 'marginal' in that they do not fit well into either Deaf or hearing worlds. Because this group tends to be withdrawn and isolated, they are often lost to service providers unless some significant event such as hospitalisation or involvement in research brings them into contact with the outside world.[56]

Evidence suggests that each of these lifestyle choices has its own potential advantages and disadvantages. For example, individuals who choose to identify strongly with the Deaf community may have a strong sense of belonging and a platform for their demands; but like members of other minority groups, they may become objects of discrimination. 'Assimilationists' is the name sometimes given to members of the second hard of hearing group. They choose to preserve an illusion of equality by 'passing' in the majority hearing culture, but may experience some sacrifice of self identity in that their hearing impairment is not always considered.[57] Bicultural individuals who move fairly easily between the Deaf and hearing cultures have sophisticated flexible or adaptable social skills, but may experience a lack of belonging or a clear sense of identity. Finally those who choose to withdraw or become isolated may experience loneliness and depression even though they may be spared considerable hearing loss related stress and embarrassment.[58]

Because most people who experience acquired hearing loss, have already established lifestyles, marriages, families, careers, leisure and social activities, they understandably are inclined to maintain these lifestyles; in other words, they would choose to remain 'assimilated'. In many instances as will be seen from this study, with good use of assistive aids and other resources, continued assimilation is possible, provided that situational limitations are accepted. However, even with a strong assimilation position, change must be acknowledged. This is illustrated in the following discussion of bereavement stages.

BEREAVEMENT STAGES

The acceptance of acquired hearing loss is deeply rooted in the need to acknowledge and to grieve for what has been lost. Stages from disability and bereavement theory have been borrowed to describe the journey taken by the hearing impaired individual.[59] These vary, but usually include some aspects of the following: denial; anger; guilt; depression; and adaptation.[60] Further explanation is given for understanding these stages by adding the following points: 1) the stages do not always happen in this order; 2) there is no time limitation on any one stage; 3) not

everyone experiences all these stages; 4) some never experience any of these stages. However even after some degree of personal mourning has occurred, social interaction must still be faced.

In the following section, how these interactions differ from interactions where there is no hearing impairment present will be discussed.

SOCIAL INTERACTION

One of the primary ways in which people with acquired hearing loss are believed to differ from those with prelingual deafness is the amount of anxiety and stress they feel during the communication process. An attempt will now be made to explore these terms.

STRESS

Some researchers believe that anxiety and stress reduction are a primary motivation in human behaviour.[61] While agreeing with the universal nature of stress, it is posited that hearing impaired people feel more anxiety and stress because of their communication difficulties; and therefore they are likely to engage in more anxiety/stress reduction behaviours. Depending upon various factors, this behaviour may have positive or negative consequences. Before exploring these factors, it is appropriate to look more closely at the nature of stress.

Stress is described as a biological and psychological reaction to threatening and unpleasant circumstances in which the individual involved feels at a disadvantage.[62] The biological changes referred to include increased pulse rate, high blood pressure, perspiration, headaches, constricted blood vessels, constipation and hormonal changes. Stress is seen as a normal reaction and can even be helpful at times such as when it signals danger. Like most psychological mechanisms, stress is subjective[63] meaning that only limited generalisations may be made about its

functioning, for example, stress generated in a given situation may act as a challenge to one person and stimulate fear in another.

In considering the experience of hearing impaired people, researchers suggest that prelingually Deaf people, despite and because of their greater deficit, may experience less stress than those with acquired hearing loss. This may be because they are more or less resigned to their limitations and experience serious problems of communication with non-signers as purely practical in nature to be negotiated with little emotional investment, rather like travelling in a foreign country.[64] However, the response does appear to be variable since other members of the Deaf culture have admitted to experiencing encounters with naive hearing people as 'ego deflating'.[65] Another point made is that if the sound of a conversation happens to be emanating out of eyesight, Deaf people may not know that they are missing anything. Because the residual hearing of hearing impaired people alerts them to conversations even when the content is not understood, they are often more aware when they are missing discourse, and therefore, are vulnerable to accompanying feelings of exclusion and frustration.[66]

Trychin, on the other hand, suggests that the most frequent and intense stress is straight forward and results from what he calls 'process problems' in communication.[67] He emphasises the mechanics rather than the content of communication, and points particularly to situations which exacerbate the strain needed to hear such as noisy backgrounds, conversation with more than one person at a time, the unavailability of telephone amplification devices, and interference produced by tinnitus. The people in this study reinforced this position focusing on the strain resulting from the unpredictable conditions affecting lipreading skill.

STIGMA

The presence of destructive attitudes in society towards people with acquired hearing loss or late onset deafness is sometimes referred to as 'stigma'. This is a term used by Goffman to describe a subjective and social phenomenon experienced

by people who have difficulty hearing, as well as by those with other 'discreditable traits' of one sort or another, such as, mental illness, alcoholism, or physical deformity.[68] He uses the term to describe the aversion to and casting off of disfigured members of society, and sees the ancient Greeks as the civilisation which first made use of this practice. As a culture, they were enthusiastic about visual aids and liked to cut or burn into the body a 'sign' or 'stigma' that announced that the bearer was a slave, a criminal or a traitor. Such a person would be seen as blemished, ritually polluted, and to be avoided especially in public places. The concept of 'stigma' has often been evoked as an explanation for the difficulty hearing impaired persons have in making sensible adjustments to their disability. Because they are so fearful of encountering elements of 'stigma' in their social life, people with an acquired hearing loss often prefer to be lost in the hearing world than identify in any way with the Deaf community by learning to lipread, to Sign, or even to wear a hearing aid.

When considering the negative attitudes which acquired hearing loss could provoke in the people inflicted, four areas emerged: feelings of living in two worlds, difficulties resulting from disrupting taken-for-granted interactions, invisibility of the disability, and the over use of the psychological defence of denial.

SUMMARY

The discussion in this chapter gives an overview of the nature of acquired hearing impairment as it is medically and audiologically distinguished from prelingual deafness. The literature argues that the most crucial factors when considering adjustment and rehabilitation for those inflicted are the time of onset and the degree of loss.

The literature also postulates that people who acquire a hearing loss of any degree are in danger of maladjustment because they have lost their place and identity in society and no longer feel they belong fully in either the hearing or Deaf worlds.

Finally, it is re-argued that an understanding of the systems perspective, which takes into account the multi-faceted and rooted in context nature of hearing loss, is essential if a way forward is to be found for appropriate provision.

The next chapter will complete the 'double focus' foundation of the study and introduces the nature of intimate relationships specifically that of contemporary marriage.

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CHAPTER IV AN INTRODUCTION TO RELATIONAL PROCESSES AND INTIMATE RELATIONSHIPS

INTRODUCTION

A recurring theme in the literature is the overwhelming importance of the ability to hear in two relational processes: sociability and intimacy.[1] Before the impact of hearing loss can be assessed, it is important to have a deeper understanding of how these two processes operate and the specific influence of gender.

Evidence from the field of Deafness suggests that even a modest hearing loss gravely hampers relaxed and easy sociability. In most cases understanding and enjoyment depend not only on meaning, but also on the context and inflection of words, quick repartee, interruptions, jokes, nuances and word play. Although hearing impaired people may long to integrate and affiliate with such convivial groups, they often find themselves cut adrift feeling more and more excluded. Orlans[2] even suggests that except for those who Sign, are excellent lip readers, or whose hearing is completely corrected by an aid, social conversation between a deafened and hearing person is seldom both full and relaxed. Rather there are only varying degrees of effort and care, fatigue, tension, truncation and/or silence.

Jones, Kyle and Wood reveal a similarly sad picture.[3] Evidence is presented to suggest that the disturbance in the ease of communication caused by a hearing impairment is likely to curtail both physical and emotional intimacy. This study provides evidence to suggest that the current literature presents a very limited perspective.

In this chapter there will be a detailed examination of the relational processes of 'intimacy', 'sociability' and an extensive discussion of how men and women differ in their requirements of both. This is followed by a discussion of the impact of hearing loss on intimacy and an introduction to the Epigenetic Principle, and the Circumplex Model of Families. Distance management and the breakdown of

intimacy will be explored and finally an overview of contemporary marriage will be given. This latter section begins with an examination of the popularity of marriage today, and follows with a discussion of major social trends: cohabitation, divorce, and reconstructed marriages.

INTIMACY

The family therapy literature suggests that today's popular literature presents intimacy as an ideal type of highly valued relatedness,[4] and it has been called an ideology in its own right.[5] Although intimacy is frequently referred to, in fact, the research literature has barely paused to define, conceptualise, or validate its nature.[6] The result is a scholarly disagreement about where 'intimacy' fits in with other relational processes, and also whether or not it is an emotional luxury incompatible with the actual life-styles, values and predispositions of many economic and cultural groups, particularly for males. Intimacy seems often to be confused with other relational processes such as self-disclosure, attachment/caregiving, sexuality, and cohesion. Since this concept creates so much confusion, a satisfactory definition is needed.

INTIMACY DEFINED

It is important to develop some kind of conceptual picture of the nature of intimacy that is relevant to contemporary marriage and partnership, specifically when one partner has an acquired hearing loss. Olson suggests an introduction to the concept when he draws the distinction between 'intimate experiences' and 'intimate relationships'.[7] He describes an intimate experience as a feeling of closeness and sharing with another in one or more of seven areas. He suggests that it is possible to have intimate experiences with a variety of persons without having or developing intimate relationships. An intimate relationship is generally one in which individuals share intimate experiences in several areas, and there is the expectation that the experience and the relationship will persist over time. The seven types of intimacy originally described by Olson are 1) emotional intimacy- experiencing a

closeness of feeling; 2) social intimacy-the experience of having common friends and similarities in social networks; 3) intellectual intimacy-the experience of sharing ideas; 4) sexual intimacy, the experience of sharing affection and/or sexual activity; 5) recreational intimacy-shared experiences of interests and hobbies, mutual participation in sporting events; 6) spiritual intimacy, the experience of sharing ultimate concerns, a similar sense of meaning of life and/or religious faith; 7) aesthetic intimacy-the closeness that results from the experience of sharing beauty.[8]

As this definition points to a wide range of shared activities, it allows for more flexibility than is sometimes attached to this term. In reviewing other definitions, some emphasise the experiences while others emphasise the relationship. In Sternberg's work on the concept of 'experienced love,' three components emerge: intimacy, passion and commitment.[9] He describes the intimacy component as largely, but not exclusively the emotional investment in the relationship. He calls it the 'warm' component in that it evokes feelings of closeness, bondedness and connectedness. It makes it possible to trust others, and to confide one's deepest fears, hopes and dreams. Although researchers vary in their understanding of the intimacy concept, all agree in perceiving intimacy as the emotional component of a loving relationship although this is rarely explicitly stated.[10] Instead, words like warmth, sharing and acceptance are used to describe the nature of intimacy. It may even be inferred that experiences of intimacy set in motion cycles of affirmative exchanges which may lead to mutual growth and development.[11] The literature also cautions that although experiences of intimacy may seem all encompassing at the time, their actual content and meaning may be much more limited. It is argued that intimacy within an enduring relationship is a process which occurs over time, and is never complete.[12] This implies that there is usually some aspect of 'relating' that needs attention.

Another common thread in the literature on intimacy is how the capacity to participate in it varies between men and women. This assertion will now be briefly explored.

GENDER AND INTIMACY

Researchers argue that males find intimate experiences and relationships more difficult than women, and if they are able to relate in this way at all, it is only with their wives inside the marriage relationship. This is believed to be the case because qualities sometimes associated with intimacy such as closeness, empathy, and caring are essentially feminine characteristics.[13]

MASCULINE STYLES OF RELATING: SOCIABILITY AND LOVE

The concept of sociability describes a set of relationships in which men are likely to be involved. Here enjoyment is arranged around specific tasks and activities. It is likely that this form of sociability will emphasise doing things 'side by side' in group settings rather than relating in dyads; and the relationships tend to be context bound rather than free floating. Relationships formed in this manner are relatively shallow in that personal worries and other matters of consequence to the self are rarely discussed. The bantering, kidding and needling which occurs on such occasions reinforces the moratorium on self disclosure.[14] The literature suggests that men rarely disclose their feelings unless they wish to gain advice, information or a knowledgeable opinion. Therefore, their first priority is often problem solving which may fit in with their task orientation to life.[15] Wynne argues that this is actually a realistic relational process strategy.[16] He notes that some relationships are overwhelmed by trappings of intimacy, and consequently neglect the less glamorous relational processes such as problem resolution and attachment/care giving. However, other researchers suggest that men's refusal to share themselves more openly with their wives has a paternalistic component. For example, the husband imagines that his wife couldn't understand or solve the problem that is worrying him, so prefers to protect his wife rather than share it, when in fact he may be protecting his own image.[17]

Thus, husbands and wives usually approach each other from different worlds, within which they are likely to have developed very different sets of assumptions. These different assumptions are often ignored by men; women, on the other hand, are more likely to be aware of them and attempt to bridge the gap. Mansfield and Collard argue that here is the paradox of modern marriage.[18] On the one hand, there is the common expectation that the roles of modern spouses are symmetrical and a kind of symbiotic fusion takes place. Whereas the reality demonstrates that it is the capacity to recognise and integrate differences between the two widely contrasting gender worlds of experience which is the true challenge of marriage today.

HEARING LOSS AND INTIMACY

The implications of the research on intimacy for this study suggest that a person's hearing loss, regardless of severity, should never be seen as the prime or only factor precipitating the breakdown of a marriage or of intimate relationships. Other salient factors discussed have been class, gender and mental health. However, there is no doubt that a hearing loss will dramatically curtail more masculine styles of relating such as sociability. Support may be found for this argument when reviewing research done by Criswell.[19] His evidence suggests that acquired hearing loss has a more devastating effect on men than on women. This may be related to men's socialisation in a dominant group as their 'given superiority' makes it more difficult for them to handle their own vulnerability, especially when it deprives them of the conversational control to which they are accustomed.

Differing socialisation patterns also mean that men and women are likely to talk about their hearing loss in different ways. Kyle, Jones and Wood find that women are more likely to express frustration about their loss while men are more likely to joke about it.[20]

Returning to Wynne's scheme for relational processes,[21] although 'intimacy' is perceived as rare, his other relational processes are fundamental and will be used in

Chapter VIII to analyse the findings concerning continuing relationships. A brief description of them will be given here.

A. THE EPIGENETIC PRINCIPLE

Wynne explains that this concept refers to events of 'becoming' ('genesis') that built 'upon' ('epi') the immediately preceding events.[22] He sees this principle as one which is generally accepted among scientists and sets limits on the range of variability, but that within this range, random variation takes place. Wynne's Epigenetic Schema develops as follows:

1. ATTACHMENT AND CAREGIVING

Our understanding of attachment/caregiving processes is largely drawn from Bowlby.[23] His definition is derived from his observations of young children when they were separated from or lost their mother. Bowlby believes that attachment behaviour is biologically based and may be found in the primates of all species, and is therefore the prototype of all parent-child relatedness. He suggests that attachment in adults is an expression of the same emotional system as that in children.

2. COMMUNICATION

At a very general level, communication is defined as a symbolic and transactional process, that is the process of creating and sharing meanings. It is symbolic in that words are used as symbols to transmit messages. It also includes the whole range of nonverbal behaviours, for example facial expressions, eye contact, gestures, movement, posture, appearance and spacial distance.[24]

3. JOINT PROBLEM SOLVING

When the above relational tasks have been mastered to a certain degree, satisfactory problem solving is more likely to develop. This process emphasises the need for

shared engagement in day-to-day tasks, interests, and recreational activities. When transitions or crises occur during the Family Life Cycle, the joint problem solving skills are 'in place', and may be drawn upon to cope with these extra stressful times. If this effort is not made, problem solving becomes ineffective, indecisive and disorganised resulting in dysfunctional families at times of transition.

4. MUTUALITY OR THE SHAPING OF COUPLE RELATIONSHIPS

Wynne uses the term 'mutuality' to refer to the partners' shared commitment to one another to shape their relationship as the life cycle unfolds.[25] The relational process of 'mutuality' begins with the recognition of difficulties that cannot be resolved within the framework of prior forms of relatedness such as problem solving; and involves renegotiation and sometimes transformation to new patterns of relating. This means that there may be an expansion, a narrowing, or an ending of this relational system altogether.

Because 'mutuality' involves a commitment to an active shaping of the partnership, as opposed to a passive acceptance of it, the precise processes involved with reference to this study need to be investigated further.

4A. MUTUALITY: DISTANCE MANAGEMENT

Although the sociological literature continually points to a gender difference in the capacity for intimate experience, the marital therapy literature has a different focus. It suggests that the dilemma of all enduring relationships where there are differences, is not only the establishment of some form of intimate experience, but also its management within the partnership. This is acknowledged in Askham's work on 'identity' and 'stability' in marriage.[26] Clulow and Mattinson describe the problem in the following way:

"...couples are engaged in a kind of dance, moving towards each other and then drawing apart constantly searching for a comfortable balance in their relationships. Frequently the balance is no sooner found than upset again."[27]

Thus personality types and personal preferences and experiences are another dimension in the management of the appropriate distance required for intimacy. The literature also infers that the ever shifting balance or amount of intimacy, (defined here as closeness, bondedness or connectedness), for one couple may be different for another. It is argued that it is only through experience that trust is built up, along with the feeling that it is safe to put oneself in the hands of another. Clinicians suggest that a characteristic of an adequate marriage is the ability of its partners to strike a balance between over and under engagement.[28] Traditionally employment is one of the main areas of life which enables a married couple to achieve structured distance from each other.[29]

Although often unconscious, clinicians suggest that the management of distance and intimacy in enduring relationships is a delicate and continuous process which is on going. Sometimes an 'end' is required to the process altogether and a breakdown may occur as will be seen in the next section.

4B. MUTUALITY : BREAKDOWN OF INTIMACY

Although the literature suggests that class, gender and mental health are factors which influence the capacity to form intimate relationships, there are other factors involved in the complete breakdown of intimacy through death and divorce.

Most researchers agree that the death of a spouse is usually harder on the man than on the woman. Although it may be harder on women economically, men are more likely to become socially isolated as a result of becoming widowers. Reasons for this are threefold: Firstly, the mother is usually the one who brings the family together.[30] Without her presence, the family may see the father less. Secondly, women are seen to have more mutuality and intimacy in their own friendships

which make it easier to adjust to widowhood. Thirdly, because traditionally men rely only on their wives as confidantes, when the wife is gone, they have no one with whom to share their feelings.[31] The widow and widower in this study will be discussed in Chapter XII.

Clulow and Vincent argue that a similar experience takes place for men after divorce.[32] In view of the fact that men often express their feelings only to their spouses, if at all, a wife's departure may not only close down the social network which she has created and maintained, it may also remove the only confidante the man has. However, it is also pointed out that by the time the marriage ends, it is likely that each partner has stopped listening to the other and intimacy may have been replaced by power struggles. One fifth of the people in this study were divorced.

4C. MUTUALITY: LEISURE PATTERNS

The literature suggests that for some people there is a clear block in their lives called 'work' which has negative or positive connotations in terms of enjoyment; and there is a clear block of time that may be termed 'leisure' within which enjoyment may be pursued in various ways. Rapoport and Rapoport argue that this view is too simplistic.[33] They suggest the situation is more ambiguous in that there are degrees of flexibility not only in the introduction of pleasurable activities in to work, but in the dispersion of work into other situations.

Mutuality in all its forms will be discussed further in Chapter VIII. The focus now shifts to a second family schema which has been used in this study for analysis.

B. THE CIRCUMPLEX MODEL OF MARITAL AND FAMILY SYSTEMS

Another way of examining specific dimensions in family life has been developed by Olson, Sprenkel and Russell and is called the Circumplex Model of Marital and Family Systems.[34] This model includes three dimensions: cohesion, adaptability and

a facilitating communication. It is possible to view a familys' cohesion and adaptability on the intersecting lines of an axis. Communication, on the other hand, is the dimension that facilitates a specific family's movement along the cohesion and adaptability spectrums.[35]

For example, families with extremely high cohesion, the measure of how close to each other family members feel emotionally, are often referred to as 'enmeshed'. This means they are involved to the point where the experience of family members allows for little self fulfilment or autonomy. In examining the dimension of cohesion on a spectrum, 'disengaged' families are at one end and 'enmeshed' families are at the other end. Communication between members helps to develop, change, or maintain the pattern of cohesion.

The other primary dimension, adaptability, may be described as "the ability of a marital/family system to change it's power structure, role relationships, and relationship rules in response to situational and developmental stress".[36] As a dimension, it bears a strong resemblance to aspects of the relational process of mutuality. It operates under the assumption that family systems constantly restructure themselves as they pass through the predictable developmental stages as illustrated in Chapter IX.

Adaptability also has its own spectrum with 'rigid' families who suppress change and growth situated at one end, and 'chaotic' families who never stop changing at the other. Again it is the facilitating communication which helps to sustain, develop, or change the adaptability within family patterns. Researchers suggest that functional as opposed to dysfunctional families are likely to make good use of communication in this way.

In this thesis for the purpose of analysis, the family dimensions outlined in the circumplex model will be subsumed under the Epigenetic Principle.

The Epigenetic Principle and an understanding of the Circumplex Model have been used to analyse the findings in this study specifically in families where one partner is hearing impaired. However, before this is discussed, it is first necessary to provide some background material on contemporary marriage. Since contemporary marriage is one of the contentious social issues of the latter half of the twentieth century, it is important to look at some of the factors which are causing the present turmoil.

THE NATURE OF CONTEMPORARY MARRIAGE: AN OVERVIEW

Recent years have seen many changes in the patterns of marriage and family life. In a relatively short period of twenty-five years, conventional family life has been condemned for its suffocating intimacy,[37] denounced as a system of mystification, scapegoating and violence,[38] and identified as a site of female subordination and exploitation.[39] However, in spite of this onslaught of academic abuse, the family has not been abolished and continues in both traditional and altered forms. Although the institution of marriage survives, there is empirical evidence to suggest that there are 'troubles' of the type that will not disappear by labelling them social constructions.[40] Perhaps these 'troubles' are partly related to the disjunctions which have been created as the institution of marriage moves from being a legalistic institution to becoming more humane in its understanding of the complexities inherent in family life. This process of 'transition' has brought with it the confusion that often accompanies rapid social change.[41]

While the functionalist's view of marriage is discussed in Chapter II, the companionship model is more contemporary and is focused on the personal relationship between the two spouses. It involves shared activities, common interests and mutual association. There is also the built-in expectation of intimacy, communication, sharing feelings, equity and mutual decision making. In contemplating these two marriage models, present day theorists point out that both of them contain elements of the other. For example in the companionship model, the husband is still expected to be the provider when the wife withdraws from work

and they begin a family. Despite the wife's change in status, ideally the focus of marriage is still on the personal and the affective. Conversely, affective characteristics still have a place in the institutional marriage. The critical difference between the two models is that when love is present in the institutional marriage, it is welcomed; but it is not essential for survival. In the modern trend towards a companionate model, the absence of love or happiness is often grounds for its dissolution since this shift has brought with it an accompanying rise in expectations.[42] This understanding of contemporary marriage suggests that marriage the institution now coexists with marriage the relationship.[43]

It is then argued that this is the central paradox of marriage today: the relationship is thought to be all important, and yet people still seek the institution. It is reasoned that it gives one a place within the family and a sense of continuity. Also it is a natural event, and indicates adult status and seriousness of intentions.[44]

Finally, Clulow suggests that there are four processes which are relevant to our understanding of contemporary marriage. These are the privatisation of marriage, the pursuit of the egalitarian dream, the decline of absolute values and the rise of relativism, and the shifts from rights to responsibilities.[45]

While it is argued by some that marriage is an outdated institution as so many people are leaving it or being confused by it, the situation is more complex as emerges in the next section.

POPULARITY OF CONTEMPORARY MARRIAGE

Marriage as an institution is thriving despite setbacks and criticism. At present about 390,000 marriages occur in Britain each year. This makes Britain and Portugal the countries which have the highest annual marriage rate in Europe.[46] This is 7.0 marriages per 1000 eligible population and compares with 10.0 in the USA.

Although the twentieth century has brought with it a steady increase in the popularity of the institution, this trend has slackened in the last decade in the UK. Since the early 1970's, annual first marriage rates have fallen especially for those under 25. Also the average age of first marriages which reached an all time low in 1970 has been rising.[47] Although there has been a steady decrease in first marriages, there has also been a steady increase of second and subsequent marriages so that this group now represents 35% of all marriages. The increase of second and third marriages is due to the greater ease of leaving unsatisfactory marriages following the passage of two acts: the Divorce Reform Act of 1969 which introduced the concept of 'irretrievable breakdown'; and the Matrimonial Proceedings Act of 1984 which allowed people to petition for divorce one year after marriage rather than three.[48] The exact reasons for the slowing down of marriage rates are unclear, but are thought to be related to increased cohabitation, more positive attitudes towards delayed marriage in the younger generation, and economic changes which make early marriages more difficult.[49]

CONTEMPORARY TRENDS IN THE COUPLE RELATIONSHIP

COHABITATION

The increase in the practice of cohabitation has been linked with the present decline in the absolute numbers of marriages in Britain. The discussion has been about whether cohabitation may be seen as a 'trial period' leading to the marriage or a replacement of it. Statistics show that the numbers of cohabiting couples have continued to rise so that for those married in 1987, more than one half have previously cohabitated. This means that cohabitation may now be considered the norm especially for couples at the opposite ends of the social scale.[50] However, although it may be the norm, there is no indication that it is a satisfactory response to the dilemmas presented by contemporary marriage. Figures recently published in 'Population Trends'[51] and based on statistics from the 1989 OPCS General Household Survey suggest that the couples who live together before marriage are

more than 60% likely to divorce than those who do not do so. A similar trend has been found in the USA and Canada.

Despite these negative statistics, there is evidence to indicate that contemporary cohabitation represents a wide range of relationships. Firstly, the present rise in cohabitation may be connected with the higher levels of parental divorce. Having experienced first hand the failure of their parents' marriage, the children are inclined to approach formal marriage and its accompanying commitment with extreme caution. Secondly, there are stable relationships which may have evolved from earlier relationships or shared accommodation. And thirdly, there are cohabiting relationships with little expectation of permanence.[52]

DIVORCE

The single most significant social trend in post war Britain has been the steady escalation of marital breakdown sometimes referred to as mass divorce.[53] Between 1960 and 1980, divorce increased fivefold. Today approximately 160,000 divorces take place each year although the proportion of divorced men and women in the adult population is only 5%.[54] Rates of divorce have been more constant since the late 1970's and Denmark has now succeeded Britain as the European country with the highest divorce figure.[55] The implication for today's marriages is that one in three now taking place is likely to end in divorce before the 30th anniversary of the couple.[56]

Researchers suggest four reasons for these dramatic trends: the emancipation of women,[57] the demand for more intimacy within the marital relationship, the stress which this and other changes cause as marriages attempt to find a balance between the institution and the relationship, and the fact that everyone is living longer meaning that being monogamous requires more restraint for a longer time.[58]

In fact, the psychosocial factors discussed so far suggest marriage now requires a new set of 'skills' for which couples have no preparation. Since very little

education and support are offered in handling companionate marriages, divorce appears to have become a substitute solution.[59]

Thus, for most couples, divorce continues to bring personal pain, guilt, and a sense of failure at having fallen short of the ideal of establishing something permanent. It can have adverse effects on the health of those involved particularly men. Although conflict may have led the partners to the divorce court, the process of divorce may initiate further conflict over property, custody, access and maintenance arrangements. Sociologists maintain that it is more helpful to see divorce as a process rather than a status: this is because it involves movement through a number of personal, emotional, material , economic and legal transitions.[60] It has been observed that all the factors have the capacity to become enmeshed in a complex web. The evidence suggests that one way couples attempt to neutralize the tensions experienced is to marry again.[61]

REMARRIAGE/RECONSTRUCTION

Approximately one marriage in three is now a remarriage for one or other of the partners. The most common form of remarriage is between two divorced partners. Some 50% of divorced men and women remarry within five years.[62] The rates for remarriage are three or four times higher for men than for women and the rate of re-divorce is also gender specific.[63] Divorced men who remarry are more than one and a half times as likely to divorce as single men of the same age marrying for the first time; for divorced women, the chance is twice that of their first-married counterparts.[64] There are about 120,000 remarriages each year in Britain.[65] One interesting characteristic of remarriage is that there is a tendency for men and women to choose marriage partners who are unlike themselves in terms of age, educational background and class. In the North American literature, this practice is known as heterogamy.[66] Unfortunately there is not room in this thesis to discuss further contemporary family variations such as step families, one parent families, and dual earner marriages. However, it is to be noted that they exist and have

become a powerful force in the social construction of the term 'family' and in family social policy.

SUMMARY

In this chapter there is a detailed discussion of contemporary marriage and the relational processes which take place within its boundaries.

The overwhelming impression in the literature is that marriage is here to stay, but it is an immensely complex relationship which is undergoing a period of painful transition as individual couples attempt to find an appropriate balance between the 'institutional' and the 'relational' in their lives.

In this chapter and the previous chapter, the 'dual focus' of the study, namely the nature of hearing impairment and the nature of contemporary marriage, has been introduced. This was done to give a context to the rest of the study. In the next two chapters, the focus will shift to examining the nature of acquired hearing loss experienced by people in the study, and what rehabilitative devices and strategies were available to them.

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CHAPTER V THE NATURE OF THE HEARING IMPAIRMENT: MEDICAL AND PSYCHOSOCIAL FACTORS AND REHABILITATION STRATEGIES

INTRODUCTION

As we have seen, clinicians and researchers believe that people who acquire their hearing losses at an early age before the acquisition of speech, and people who suffer from the greatest deficit (that is severe, profound or total loss), are the most likely to experience chronic difficulties of one kind or another throughout life.

However, while this may be broadly true at a general level, this particular study indicates that a more complex pattern of events emerges in that psychosocial factors acquire greater importance, and therefore, must be examined in detail. And, as we shall see, psychosocial factors might, in fact, be more accurate predictors of risk and adjustment than medical/audiological factors. This position is strongly argued by the Oyers when they say:

> " ...An additional variable of tremendous import is the extent to which family members and friends understand the psychological, social, educational, and vocational implications of hearing impairment and are motivated to initiate and to respond meaningfully to a course of action to support the hearing impaired person."[1]

This suggests that within family life there are in fact compensating psychosocial factors which balance, modify, and monitor the crucial medical/ audiological factors of time of onset and degree of deafness.

Before looking at the psychosocial factors, the people in this study will be introduced accompanied by an analysis of their medical/audiological details (See Appendix I for full profile of each couple).

Although no evidence was available from pure tones audiograms, rough approximations could be made on the basis of discussions with the study participants. On this basis, Anne, Frank, Max, Theo, and Rachel had a mild/moderate loss while Joe, Martha, Richard, Barbara, and Henry had moderate/severe losses. Two people, Anthony and Arthur, had profound losses, and Christine, Joy, Grace, and Sam also had near total losses. All but one of the latter group of four, had received cochlear implants.

THE ADJUSTMENT FACTOR AS IT RELATES TO MEDICAL AND PSYCHOSOCIAL FACTORS

If the literature is correct in suggesting that the time of onset, and degree of loss are the crucial factors in predicting adjustment, difficulty in adjustment would most likely be found in two particular groups. The first group, Barbara, Henry and Arthur, were born with severe hearing losses and required 'special education'. The second group, Anthony, Joe, Christine, Grace, Joy, and Sam, had all acquired severe/profound hearing losses in young or mid adulthood; and therefore, in comparison with other people in the study, required the most 'lipreadability' from hearing people. The question could then be asked: did these two groups and their families show signs of their high vulnerability in comparison with other people in the study? When the lives of people in the two so called 'at risk' groups were analysed, a complicated picture emerged.

Firstly, the deafened men in the second group had all married remarkably capable hearing women. While they were sensitive and understanding with their husbands, developing compassion as they went along, they were also people in their own right, simultaneously nurturing families, and holding down responsible demanding jobs. What this meant was that these key women through their love and understanding held their husbands 'in place' in the hearing world regardless of the difficult experience of being deafened.

On the other hand, Henry, Arthur, and Barbara, did in fact form a vulnerable 'at risk group'. This was because all three identified with prelingually Deaf people and were open to their emotional needs and demands. Yet they lived and worked mostly in the hearing world and had married quite formidable hearing partners. This meant that the understanding gap between themselves and their partners was wider than it was with the first group because their marriages contained two separate cultures beyond that of being different genders.[2] For example, Arthur felt most comfortable among people who used BSL; and Henry and Barbara, although not fluent Signers themselves, felt the same. While this could be a creative difference and distance, it could also create additional difficulties.

Secondly, because Joy, Grace and Christine had both hearing losses, and were in the last stage of the family life cycle, they might be thought to be in 'double jeopardy'.[3] But as they had all received cochlear implants, medical intervention had transformed their previous marginal status and they had become reassimilated to a considerable degree into the hearing world.[4]

Thirdly, Anne and her husband, Adam, divorced two years after interviewing was completed. Although the literature is divided as to whether or not divorce is an expected part of the life cycle or course,[5] the breakdown of a partnership does cause stress and difficulty.[6] In this case the hearing impaired partner, Anne, had been recently diagnosed as having a mild loss. From the medical/audiological point of view, she was the least 'at risk' individual in the entire study. However, because of a complicated set of psychosocial and career factors, she was the most dissatisfied with her present partnership and therefore open to other loving relationships.

In continuing with the review of medical/audiological factors, the type of hearing impairment will now be discussed.

TYPE OF HEARING IMPAIRMENT

All but one person in the study had sensorineural losses. Etiological factors varied. Sam and Anthony were deafened from drug toxicity. Henry and Barbara had mothers who had contracted rubella in the first three months of pregnancy. Three people mentioned severe illnesses contracted in infancy or childhood: Christine had contracted pneumonia, Martha scarlet fever, and Joe diphtheria. Frank, Theo, and Max had presbycusis. Frank and Theo knew others in their families who were also hearing impaired and so acknowledged a hereditary component in their condition. A fifth group, Grace, Arthur, and Rachel saw their hearing impairment as primarily a hereditary condition. Arthur belonged to a family where each male child had a 50% chance of becoming deaf. A sixth group comprised two people who had contracted adult illnesses. Joy had contracted meningitis and Richard was still having erratic attacks of Meniere's Disease. Rachel was the only person with a conductive loss and she had otosclerosis.

Besides the illness or genetic condition which resulted in the hearing impairment, there were often additional side effects which will now be discussed.

SIDE EFFECTS

Joy, Anne, Arthur, Richard, and Sam all had difficulty with tinnitus which is the most common side effect in the study. Joy described the unpleasant sounds :

> "...It's just a continuous ringing in the ears that goes on and on like organ music that plays the same three notes over and over again...it would drive me mad...but...(I) train...(my)self not to listen."

Anthony and Joy mentioned the use of 'maskers' to help with the tinnitus. These are alternative sounds emanating from a hearing aid or cochlear implant which eclipse the sound of the tinnitus. Joe and Richard complained of vertigo and Joe and Mary complained of recruitment.

RAPIDITY OF LOSS

Five people in the study experienced sudden and traumatic loss of hearing. Sam at 18 and Anthony at 31 were deafened by drug toxicity. Richard at 60 had experienced sudden attacks of Meniere's Disease. Joy at 35 was deafened during a bout of meningitis. Grace and Christine acknowledged they had acquired severe/profound hearing losses in mid-life although onset was likely to have begun much earlier.

For the remaining nine people, hearing impairment was present at birth or came gradually, and therefore, made a less dramatic impact on peoples' lives.

To begin our analysis of the importance of psychosocial factors in facilitating adjustment, we will first look at the use of assistive listening devices.

PSYCHOSOCIAL FACTORS AND ASSISTIVE LISTENING DEVICES

THE HEARING AID

The applied literature suggests that some assistive listening devices are helpful for those whose hearing loss is mild and who have not yet been fitted with a hearing aid, while other devices go beyond the hearing aid to reinforce listening potential in a variety of ways. The most commonly used assistive listening device is the hearing aid itself. It was originally invented by Alexander Graham Bell in 1876, but was not marketed in America until twenty-two years later.[7] Today there are basically three types described by the manner in which they are worn: body aids, behind the ear aids, and all in the ear aids. The body and behind the ear aids are available from the National Health Service. All in the ear aids must be purchased privately and are only suitable for people with mild/moderate losses.

Before looking at how psychosocial factors affect people's attitudes towards hearing aids, it is useful to look at the three phases of adjustment to hearing aid wearing which have emerged in the literature.

THREE PHASES OF ADJUSTMENT TO ACQUIRED HEARING LOSS

Kyle, Jones and Wood suggest Phase I is when the hearing loss is denied. This phase usually lasts anywhere from a few days to twenty or thirty years.[8] Phase II begins when 'the loss 'is diagnosed. In the UK, the normal procedure is the following: a) an interview with the general practioner at the local health centre; b) referral to a hospital or audiology clinic for tests; c) return to the doctor or clinic for test results; d) fitting an aid and e) final visit to receive an aid. This phase usually lasts a few months. Phase III is subsequent accommodation. It is divided into four parts: a) adjustment to the hearing aid; b) personal and social adjustment; c) vocational adjustment and d) family adjustment. This model is helpful in that it shines light on an experience which is rarely discussed and takes place mostly in the privacy of the home. This study is focused specifically on b) and d).

In analysing the responses of the people in this study, Phase I of complete denial occurred relatively rarely. Everyone began to tell their 'stories' at the time of diagnosis without mentioning lengthy periods of uncertainty beforehand. This might be connected with the personalities of the people who volunteered for the study in that they were on the whole honest and open. They also had considerable resources for managing the experience of 'loss' before the specific loss of hearing was noticed. This particular attribute may have meant that they were less likely to deny their problems. Another reason why 'denial' may not have occurred was the traumatic nature of the 'onset 'of hearing loss in five cases.

Although most of the people in the study had completed the Diagnosis Phase, four people, Anne, Sam, Martha, and Joe, had not. For various reasons, they had begun the Accommodation Phase while still theoretically in the Diagnosis Phase. This suggests that the present Bristol model is too rigid, and needs further work to reflect the fluid dimension of the adjustment process.

ASSISTIVE LISTENING DEVICES

Many hearing impaired people find that they are helped by other technical aids to daily living. These devices fall in to three categories depending upon what is being assisted: radio and television, the telephone, visual and other signals. They are viewed as being either hard wired or wireless assistive systems. The latter require a direct connection between the sound source and the listener. Wireless listening systems are divided into three primary types: audio induction loop, infrared, and FM.

The 16 people interviewed in this study varied considerably in the assistive listening devices they found useful. It might be expected that people with the least amount of residual hearing would be likely to make the most use of communication strategies in addition to listening. Although some people in the study fell in to this pattern, enough did not to suggest the situation was more complex and that multiple psychosocial factors were operating. This will be explored in the next section.

ACQUIRING A HEARING AID: COMMUNICATION VALUES IN A CULTURE AND ATTITUDES OF SIGNIFICANT OTHERS

Of sixteen people in the study, eleven wore behind the ear hearing aids. Ten people were happy to use the National Health Service Aids. Henry preferred to buy his aids privately. Eight people out of the eleven had been given two Aids. Three people, Max, Martha, and Theo, who had been given only one aid, did not know why this was so and had not thought to ask. It might be indicative of the present distribution policy of the NHS that two of these people were elderly, and the third was on social security. There was also a wide range of actual adjustment to the aids. Martha and Arthur complained that their aids hurt or did not fit properly while Arthur and Frank acknowledged that they often wore only one even though they had been given two aids. Possible reasons for their attitudes will be explained in greater detail below.

Mildly hearing impaired Anne and deafened Sam choose not to wear hearing aids. Although they represented opposite ends of the spectrum regarding degree of loss, they shared a rather stoical attitude towards life which McGill and Pearce claim is often found in British culture.[9]

Joe and Anne, also appeared to be influenced by the attitude of 'significant others' namely the parent of the opposite gender to themselves.[10] In both cases Joe's mother and Anne's father expressed a strong aversion to seeing their adult child wearing a hearing aid. For example, Joe, of Jewish descent, recalled hearing his mother say "Must you wear one"? This had the effect of delaying the wearing of an aid for at least ten years until Joe's son was born. At this point he reversed his decision since "children talk softly." Moreover, the other Jewish hearing impaired person in the study happened to have a similar attitude. Rachel, a lecturer, related:

> "...(The hearing aids) work...And without 'it', I can't function. And obviously now I have two little boys...so the first thing I do in the morning is to put my hearing aids on."

These two examples may demonstrate the influence of a culture in which verbal communication between generations is highly valued, (in this case Jewish). Both Rachel and Joe wore their hearing aids so they could hear the children.[11] Conversely, this is often not the case in English middle class culture where 'silence' may be highly valued, and interpreted as a loving attitude in that it is respectful of the other person's 'space'.[12]

ACQUIRING A HEARING AID: PSYCHOLOGICAL DEFENSE MECHANISMS AND COPING

A repeated theme throughout the study was that 'hearing aids' were acknowledged as negative objects, specifically they were seen as a crutch, a sign or a symbol of a problem which their wearers and 'significant others' wished to keep hidden. These attitudes easily led to the use of 'denial' as a psychological defence mechanism.

The use of the defence of 'compensation' was another way of coping. Joe, Rachel, and Henry expressed this in the great pride which they showed in having the highest quality, and very latest hearing aids to compensate for their lack of perfect ears.

Another coping attitude is to attempt to exorcise dislike and fear of hearing aids through positive encounters as found in self-help organisations.[13] This happened for three people in the study, Joe, Theo and Max. Joe, told the researcher the following brief story three times!

> "Did you hear...about the man...(we met) when we were in Switzerland? (attending the International Conference for the Hard of Hearing)...(the man) had on an orange...(hearing aid). And he had white hair...and I went up to him and said...I think I know why you're wearing an orange hearing aid...because you want everyone to know that you're deaf. The man said, 'Yes'."

Joe's enthusiasm for this encounter suggested that it freed him to be more himself in that it was possible to be deaf, and also an attractive extrovert male.

However, sometimes the reverse took place. The aid(s) were hidden or not worn even when obtained. After being recently prescribed two aids, Frank recalled:

> "I was conscious of 'it... (initially)...and...(I) felt slightly ashamed (I've) got this...I think your reaction is that you want to hide it...but I've grown

blase and don't mind. I think the fact that it helped me considerably...especially in hearing what some women were saying...means that I was more willing to use it."

Frank discovered in time that the visibility issue mellowed because of the rewards found in reestablishing good communication with certain valued colleagues. Since he had already fully established himself, Frank was not fearful that others would doubt his competence. However, he was not insensitive to the symbolic value of hearing aids as a sign of personal inadequacy. He recalled:

" If you just wear 'one' (rather than the two hearing aids prescribed), there's the chance somebody won't notice...it's being noticed as a disabled person I suppose. It's not disabled in the sense of being short a leg or something like that, but it is a disability; and there's the feeling you don't particularly want it publicised..that you find it difficult to understand people all at once."

Rachel had similar feelings but for different reasons. She related:

"I know there are people who don't wear hearing aids,..I think they are saying (that they are ugly)...its a vanity thing or something. With me it's simply I need to work, I enjoy my work, I have to hear."

Rachel was unconcerned about 'body beautiful' issues which she knew affected some people.[14] Joe, Henry, Frank, and Rachel had very different ways of coping with their dislike of wearing a hearing aid. As we now see, additional psychosocial factors which emerged in relation to the hearing aid were gender and developmental transitions.

ACQUIRING A HEARING AID: GENDER AND DEVELOPMENTAL TRANSITIONS

Although the attitudes of Frank and Rachel were similar in their dislike of wearing aids, their reasoning was different. Frank was consciously aware of how the aids could reflect on his professorial image. Visibility was not an issue for Rachel whose long black hair covered up her aids. Rather she was much more concerned about the inhibitions she felt when wearing hearing aids.

These findings suggest that men for various reasons are more vulnerable to feelings of stigma than are women.[15] Although the 'visibility issue' was highlighted by Frank, other men in the study had similar feelings.

Anthony, a doctor, did not wear his aids in the first research interview as it appeared easier for him to present himself as being totally deafened rather than to have the 'between two worlds' status[16] of being hearing impaired. However, from an intellectual point of view, Anthony understood perfectly how his aids helped him. Arthur's wife, Gwen, acknowledged that she looked after his hearing aid batteries whenever they were out together in public. It appeared that Arthur, a university student, was prepared to publically wear his aids provided he had his wife's support. Henry, a theological student, was the only person to own private aids which were encased in the frames of his glasses and were barely noticeable. The last man, Max, a retired headmaster, began to wear his aids after his wife died since it was only then that he admitted his loss.

On the other hand, most, but not all, of the women in the study were more 'matter of fact' in their acceptance of wearing aids and seemed less vulnerable to feelings of stigma.[17]

Three people had worn 'box aids'. Joe exchanged his box aid for a behind the ear one after his divorce in his late forties. Perhaps cosmetic value predominated over financial considerations when Joe was once again in social circulation. It was also a

time of developmental transition/crises for Joe since he was moving from a married to single state.

Arthur mentioned that he had shifted from a box aid to the behind the ears variety at the age of 14. Again it appeared that a developmental transition from childhood to puberty and the resulting social circulation might have been psychosocial factors that triggered the shift.

A third person, Barbara, alternated, choosing to wear a box aid sometimes with aids worn behind the ears at other times. She found her box aid amplification especially useful in telephone conversations. For Barbara, the utilitarian value of the 'box aid' had greater value than the cosmetic 'invisibility' of the behind the ear models. While attitudes towards hearing aids continue to vary, the men in the study were significantly more uncomfortable than the women about wearing their aids in public. Some apparently eccentric choices of 'box aids' could be understood in the context of their specific use and of developmental transitions. In the next section, there is an analysis of the way men and women in this study responded to suggestions for surgery and the use of the FM radio microphone.

SUBMITTING TO SURGERY AND THE USE OF FM RADIO MICROPHONES: GENDER , PERSONALITY, AND AGE

Grace, Christine, and Joy had been operated upon and received cochlear implants. Although Anthony, Sam, and Arthur were eligible for this operation, all three had refused. The literature suggests that women are more adventurous in trying devices, aids and methods of self help; whereas men, more accustomed to a position of control, are less likely to take such risks for fear of ridicule or embarrassment.[18] This analysis refers to men's socialisation in a dominant group which ill fits them to manage their own and other men's 'vulnerability'.[19]

Besides gender, personality and age were also significant psychosocial factors. Joy, Grace, and Christine had extrovert personalities and were highly motivated in that all three stayed in the job market. Another factor which appeared to contribute to their decision to have a cochlear implant was the attitude of their 'significant others'. For example, Joy's husband and son were very keen for her to have the implant and were undaunted by the fact that the operation was still at an experimental stage. Another motivating factor for Christine and Grace was their desire to remain as autonomous as possible despite the 'double jeopardy' which had accompanied their status as both elderly and hearing impaired people.

Rachel had received microsurgery for her middle ear condition, otosclerosis. Because her hearing deteriorated a second time, she considered the possibility of having a second operation even though this meant that she would have to leave England in order to receive it. After further consultation, she decided to concentrate instead on getting the best possible hearing aids for her condition. The attitude of Rachel's husband and 'significant other' played a part in this decision. While he was happy to support her to have a second operation, he did not consider it an emergency and had adjusted to a wife who wore hearing aids.

This section has considered the impact of gender, personality and age, psychosocial factors which influenced people in this study in their choice of whether or not to have a cochlear implant. The discussion continues with the focus shifting to the effect of assistive listening devices on family life.

ASSISTIVE LISTENING DEVICES FOR THE TELEVISION: MAINTAINING PERSONAL, COUPLE, AND FAMILY EQUILIBRIUM

Assistive devices supported or detracted from the present equilibrium or status quo in the marital relationship and in the family more generally.

Joy, Robert and Barbara found great satisfaction in the use of subtitled television because of the autonomy it gave them. Barbara made the dramatic statement that

subtitles had "saved her marriage". Apparently this was because Barbara's brother had interpreted the television for her as a child without editing. However, her more sensitive husband, Ben, did not feel it appropriate to repeat what he considered to be 'unrepeatable', specifically distasteful humour. The arrival of subtitles meant that Barbara once again had more information control and her resentment towards her husband's sensitivities vanished.

Two people had audio induction loop systems to help them to hear the television. Max's loop system had been installed by the local social services and went around his sitting room. He believed it to be of minimal help to him, (he was not a lipreader), and as a widower, he did not have a wife to interpret for him. Joe's device was attached directly to his hearing aid and he proudly stated it had been privately purchased from Switzerland.

Six people had acquired subtitles privately. Grace acknowledged she was in the midst of a campaign for enlarging the number of programmes that were subtitled.

OTHER ASSISTIVE DEVICES

Two people, Joy and Arthur, had a flashing light attached to the door bell. Arthur also mentioned a flashing alarm clock and Max, Theo, and Joe had telephone amplifiers. Theo aged 84, mentioned the usefulness of her cat. She was proudly aware that she could watch the cat's tail and body twitches to check for possible sounds. Arthur and Martha mentioned the helpfulness of their dogs. Arthur demonstrated how they had trained their dog to respond to commands in BSL. No one had a specially trained 'hearing dog' and profoundly deafened Grace was actually campaigning against them as she believed that the training involved could be done privately at less cost.[20]

SUMMARY

This chapter argues that medical/audiological factors alone are not sufficient to make accurate assessments of whether or not hearing impaired people are likely to be more or less at risk of maladjustment. Consequently, the same medical/audiological factors are not sufficient to accurately predict long term adjustment.

The findings suggest that psychosocial factors must be considered with great seriousness if a realistic and long term assessment is to be made leading to the provision of appropriate help. When the lives of the different groupings in the study were analysed, a complicated picture emerged.

Firstly, deafened Anthony, Joe and Sam had benefited from being married to remarkably capable women who were able to get on with their own lives, and simultaneously 'hold' their husbands in the hearing world. Conversely, prelingually deaf Henry, Arthur, and Barbara did not receive the full acceptance they needed from their hearing partners, making them more open to stress generally and the real 'at risk' group in the study. Thirdly, profoundly deaf Grace, Christine, and Joy were less 'at risk' because they had been courageous enough to receive cochlear implants and the attention from the medical profession which accompanied this operation. In this way their marginal 'double jeopardy' status was transformed. Fourthly, mildly hearing impaired Anne and her husband, Adam, divorced suggesting that there were multiple psychosocial factors in operation unrelated to the degree of deafness.

The importance of psychosocial factors is well supported in the literature by the 'Three Phases of Adjustment' to a hearing loss suggested by Kyle, Jones and Wood.[21] Specific psychosocial factors discussed in this chapter in relation to acquiring and adjusting to a hearing aid are communication values in a culture, attitudes of 'significant others', psychological defense mechanisms, developmental transitions, gender, personal and couple equilibrium.

Although beyond the scope of this thesis, it is essential to be aware of other areas such as employment prospects and environmental provision which would undoubtedly have their impact on total adjustment.

From the use of assistive listening devices, the focus shifts in the next chapter to a discussion of specific communication strategies used by the people in this study.

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CHAPTER VI COMMUNICATION STRATEGIES

INTRODUCTION

While the last chapter introduced the importance of understanding the impact of psychosocial factors on the rehabilitation process, this chapter will continue this theme but will focus specifically on the interaction of psychosocial factors with communication strategies.

Undoubtedly in this study the most important communication strategy was lipreading. This was because it was used by eleven of the 16 hearing impaired people who took part. Of this group, six were men and five were women. Seven people said they had learned naturally with no tuition. Four said they had attended lipreading classes. The exceptions were the people with mild/moderate losses who had not felt the need to learn an additional communication strategy. However, even for the people who had a flair for lipreading, practical and emotional difficulties arose.

In view of this analysis, it seemed important to consider the interactional components in lipreading, and the people in the study were asked: How is lipreading managed in your relationship? Who takes responsibility for seeing that it takes place? However, before looking at the findings, some additional information about the background of lipreading will be given.

The development of the art of speech/lip reading in the UK evolved in connection with the education of Deaf children. Many of the early teachers of Deaf people from the nineteenth century onward were oralist and so emphasised speech and language. Speechreading is an inevitable consequence of this approach. By the end of the 19th century, speech/lipreading was beginning to be seen as a separate skill which could assist hearing impaired people with their communication difficulties.[1]

Speech or lipreading is described as the art or skill of understanding a speaker's thoughts by watching the movements of his mouth.[2] Kaplan provides a more refined and contemporary definition: "lipreading is a synthetic cognitive skill which integrates visible facial movements with other available information in order to grasp the person's words and thoughts. It exploits the characteristics and redundancies of the language and the situation including the following: a) gestures, b) audible signs, c) situational and contextual clues and d) language structure".[3]

There are many sounds like 'm', 'b' and 'p' which are difficult to discriminate on the lips, but not aurally. Similarly vowel differences are difficult to see, but easy to hear. For this reason, it is always stressed that lip reading is not a substitute, but an adjunct to amplification.[4] Conversely, amplification is not a substitute for lipreading since most severe and profoundly hearing impaired people need to use lip reading for clarification in conjunction with powerful hearing aids or the more recent cochlear implants. Unfortunately the situation can be further complicated by additional difficulties which cause stress.

Five psychosocial factors emerged in this study to affect this lipreading process. The next section will explore them.

LIPREADING STRESS: WHEN ENCOUNTERING STRANGERS

Encountering strangers was a special area of concern for the lipreaders in this study. In this respect they shared the apprehension of people with other disabilities and people with introverted personalities. There were questions about lipreadability, acceptance, rejection, and having the skill necessary to negotiate a satisfactory encounter. These findings reflect the literature which suggests that having a physical disability magnifies the awkwardness of the first encounter.[5]

The hearing partner, Julia, of a totally deafened computer programmer, Sam, had this to say:

> "There is a built-in stress factor...and unless it is experienced directly, other people have no knowledge of it. Sam's deafness can spark off rudeness in others partly because they think he has been rude first..."

Julia recalled how Sam had parked his car in an inappropriate place. A man yelled at him. Sam, not hearing him, ignored him. This brought forth abuse. If the man had realised that Sam was deaf, and of his need to lipread, it would be hoped that a less aggressive encounter would have ensued.

Two people in the study discussed how they operated when on package holidays with strangers. Elderly hearing impaired Grace, studied all the guide books carefully before she took her holiday. She wished to appear knowledgeable and independent, positive qualities which she hoped would dilute the fact that she was totally deaf. Grace confided:

> " (My fellow travellers) are (always) horrified...to have a deaf person with them... (But in time), there are always one or two people who communicate easily. And that gives other people confidence. But you must not expect too much...it's their holiday after all."

Grace had learned to be patient, and to cope with the shock and withdrawal which her deafness provoked.[6] She had developed the art of impression management, the maximising of positive characteristics or the making of a positive impression.[7]

Mike, Joy's husband, recounted how he managed this problem, sometimes known as 'stigma management,' by behaving in such a way as to minimise the impact of a negatively valued characteristic such as a hearing loss.[8] Very early on a package holiday, he explained his wife's deafness so that her inability to respond from behind would not be mistaken for rudeness. Like the woman above, this couple had discovered that there would be a few people who made the effort to be friendly, although there were others who "didn't want to know."

As these examples convey, the hidden nature of acquired hearing loss means that decisions about how to manage encounters initially belong to the hearing impaired people and their spouses. Considerations were whether or not to disclose, whether or not the consequences of disclosure will be manageable, and whether or not it will be more effective to adopt an attitude of 'pretence'.[9] The latter strategy is sometimes misunderstood by service providers who may view it only as an inhibition resulting from low self esteem.[10] The people in this study suggested that such a view was simplistic, and that there were many factors which needed to be weighed in order to determine what was appropriate.

A hearing impaired designer, Joe, told of his difficulties in lipreading an elderly lady at the railway station of a seaside town. He said:

> "And she was nattering away...And I thought...I'm not going to tell her I'm hard of hearing...what with the sea pounding away, and with the traffic at the back. (To tell her) would have been a hassle to her as well as to me."

Joe later discovered the lady was talking about the next train to Brighton. Since this topic was of no concern to him, he felt further justified in his non-disclosure strategy.

Besides difficulties with strangers, the responses of the people in the study suggested that difficulties could occur within the family itself.

LIPREADING STRESS: WHEN INTIMACY IS LOST WITH AN ONLY CHILD

The study produced a number of striking examples where lipreading with ease had not been achieved with close family members. One failure occurred when the eight year old son of Mike and Joy was unable to accept Joy's sudden and total deafness from meningitis. Although their friends were able to adjust to Joy's special needs by following Mike's example of speaking in a slow friendly conversational tone,

their son James retreated to his bedroom and rarely attempted to make conversation with his mother and/or more generally with other women. Now, nearly twenty-five years later Joy recalled:

> " No, I can't lipread James easily. You can if you're deaf, but it's very difficult. I can read his wife very well...she chats."

Despite these authentic needs of Joy, James was unable to respond to them. How might this behaviour be explained? Firstly, James might not have received a 'suitable explanation' for his mother's hospitalisation and deafened condition at the time that they occurred.[11] This may have led to a partial grief reaction.[12] Other losses may have compounded the initial loss.[13] For example, the onset of Joy's deafness triggered a chain reaction of events that formed a family crisis: Mike and Joy were forced to cancel a business partnership, Joy took a lipreading course, they moved to a new home, James began a new school, and Joy began a new job. Also at this time, Mike was experiencing pressures at work in the printing trade. This meant, with the exception of joint involvement in Scouting, Mike's availability as a father was restricted. Unlike some couples where one partner is disabled, he was unable to compensate for the communication breakdown that had occurred.[14] Eventually, however, after a new equilibrium was established, Mike found the time to cultivate a warm and lively relationship with his son.

Secondly, it is helpful to see Mike, Joy and James as a family in the second stage of the 'life cycle' discussed in Chapter IX. It is likely that James experienced ambivalence and other confusing feelings at this time. Part of him was likely to have seen his mother's position as slightly enviable because of the special care she received from his father,[15] while another part might have felt quite hostile when her limitations frustrated his own needs. Also as Wolff, a child psychiatrist writes:

> "In middle childhood when children become aware of stigma, parental disability can be a profound source of public shame with consequent feelings

of disloyalty and more guilt when the child may wish above everything else to exchange the sick (disabled) parent for a healthy one."[16]

Thirdly, the literature suggests that an additional drawback for James may have been his 'only child' status[17] in that he had no natural ally in a brother or a sister. Joy recalled her relationship with James after she came home from the hospital:

> "I...felt very tense, awkward about...(being deafened); because I felt I couldn't do anything about it. I felt watching...(that James) seemed to be struggling...I just accepted it...but then I think I worried about James more."

Mike recounted his own efforts in trying to draw his son out with little success. He concluded:

> "James could get up and give a speech, or talk about a subject: but not hold a general...(social) conversation..."

Clinical intervention at the time of diagnosis could have helped this family to express their grief, and more specifically, to help James to relax so that he could speak more clearly and directly to his mother. Although Joy has long since accepted the situation, a closer relationship with her son is still something she longs to re-establish.

LIPREADING STRESS: THE GENDER FACTOR

Although the literature argues that men are generally the more vulnerable of the sexes in connection with adjustment to acquired hearing loss,[18] members of the study suggested that a specific and perhaps crucial factor in this adjustment was men's difficulty in lipreading other men. This was exemplified in a conversation that severely hearing impaired Joe had with his teenage son.

> "... (Peter, my son) had a tendency to talk very rapidly because he thinks so fast. I said to Peter, 'Can you please slow down a bit because you know I am deaf; and I can't follow what you are trying to tell me.' And his reply was, 'You're not deaf'."

Peter's denial of his father's deafness suggested that not only deafness, but also vulnerability more generally was not seen as a legitimate discussion topic between them.

Joe talked about his difficulty in lipreading his father with whom he had also been apprenticed.

> "He was a kind man...helpful,..(but) difficult to lipread him. He used to talk so softly, I used to want to shake him."

There were other examples where a grandfather could not understand his grandson, a stepfather could not understand his stepsons, and a son-in-law could not understand his father-in-law. Although there were definite exceptions to the pattern, it seemed persistent enough to warrant further investigation.

In looking at the effect of gender on lipreading, one must first visualise the scenario. Both participants need to feel relatively comfortable with a 'face to face' gaze and physical proximity. Although designed as a practical communication strategy for hearing impaired people, the sociological literature on men implicitly suggests that the lipreading process could be experienced as restrictive, confrontational,[19] intrusive[20] and/or seductive.[21] Although a number of factors might be responsible for this, perhaps the most dominant is English male socialisation patterns. What are these patterns, and what may their implications be for lipreading?

Although there are many exceptions especially among service orientated professionals and academics who are more likely to have androgynous traits,[22]

evidence continues to emerge from a number of disciplines that the prevailing paradigm of masculinity dictates rigid control on self expression specifically in English speaking cultures.[23] Therefore, it is not surprising for sociologists to find that interactions between men have a tendency to reflect this pattern despite a newly acquired knowledge of the damage these inhibitions do to their psyches. Allan describes men's sociable ties as being in general more 'side to side' rather than 'face to face'; to be about completing tasks rather than disclosing feelings, and to be context bound rather than free floating.[24]

While men's difficulty in lipreading other men might point to a classic phenomenon, hearing impaired women in the study had more diverse opinions. Those who were married complained about men generally only if they had specific characteristics that blocked effective lipreading such as beards, moustaches, and the use of brief speech outside of any facilitating context. Women generally have more social contact than men. Thus, the 'looking' required for lipreading comes more naturally to them.[25]

The women in this study, who had been divorced, alluded to being treated as 'damaged goods' by their former partners who were unable to cope with the developing conversational constraints or with the continuing rehabilitation required.

In general, the hearing impaired women in the study did not experience hearing impaired men or their hearing partners as problematic to the same extent as was experienced by hearing impaired men.

The discussion of the impact of gender on lip reading raises important issues. In particular it remains puzzling that men should find it so difficult to have face to face conversations with other men. Dorval's friendship conversation study has thrown additional light on this phenomenon.[26] The videos taken of male respondents, regardless of age, reveal that they could sit down and talk more or less directly to their friends; and at times, the content of their conversations was quite personal. However, without exception, they sat at right angles to each other, and rarely

looked at each other's faces; seeming to prefer to look outward and around the room. Researchers have suggested that men and boys' resistance to 'looking' could reflect their unconscious fear that the behaviour would be confused with 'staring'; and thus be misinterpreted as sexual interest, heterosexual or homosexual, and/or a desire to dominate.[27]

Researchers also suggest that it is difficult to determine what behaviour differences between males and females have their roots in biology, and what in socialisation as the latter is so powerful and so early. Studies of newborns show that parents tend to encourage more physical activity in boys and dependence in girls.[23] It was also discovered that parents talked and looked more at baby girls while they engaged in rough play with boys.[29]

While many changes have occurred in the past twenty-five years in men's understanding of their need for closeness, triggered by the human potential movement, many of these previously established deep rooted patterns and attitudes have been retained.[30] Consequently, the process of lipreading might feel like a simulation of intimacy, an experience men usually associate with wives,[3132] mistresses or prostitutes,[33] conversations between women or homosexuals.[34] Whether or not a specific man might be able to adapt to lipreading was likely to depend upon many factors such as his age, job, education, upbringing and personality.

From the discussion of the impact of gender on lipreading, the focus now shifts to the stress which the need to lipread may cause within committed partnerships.

LIPREADING STRESS: WITHIN COMMITTED PARTNERSHIPS

Psychoanalytic and marital interaction theory informs us that in intimate relationships which have persisted over time, there is some kind of emotional 'fit' which enables couples to make adjustments to each other.[35] When this does not happen, it is likely that one or both partners have never developed a capacity for

intimacy. This argument is supported by Noller's work. She examines 'looking' behaviour in couples with marriages that she describes as 'satisfactory'. Noller states:

> "the amount of looking one spouse does in a particular interaction role seems to affect the amount of looking the partner does in the reciprocal role. So if the speaker is looking a lot, the listener is also likely to look a lot."[36]

The positive correlation between looking behaviour and satisfactory relationships, that is 'good enough' marriages,[37] suggests that the stage is already set for communication and/or intimacy when a partner has an acquired hearing loss.

In hindsight, Mike acknowledged the importance of lipreading:

> "I think you come back to a combination of two things...one is Joy's ability to lipread and (the other) is (that)...I talk fairly clearly...and it makes conversation a lot easier than it could be."

Mike added that they had made a habit of talking things over with each other; and there had not been any reason to change when deafness had struck Joy eighteen years into the marriage.

This remark suggested that Mike did not fit the withdrawn husband characterised in the linguistic literature.[38] In fact, Noller would probably call him a 'high adjustment husband', a typification she discovered in her study of gaze behaviour in married couples. She noticed that certain men were more likely to look at their wives while listening. She concludes that this behaviour suggests a real desire on the part of the husbands to understand rather than to control their spouses. Hence by implication, the 'looking' necessary for lipreading was likely to help mutual understanding and cementing of all intimate relationships regardless of auditory capacity.

However, even when there was a strong loving rapport between spouses, frustration occurred when quick responses were required. Julia recalled such an incident with her deafened partner, Sam:

> "It was like having to get through a brick wall. It was nothing to do with him, and nothing to do with me...and you had to get through that. We don't always and then I throw something...but not so he can see."

Slowness in communication is not necessarily always the result of deafness, nor is impatience always felt most strongly by the hearing partner as individual personalities were a factor. A couple who were retired teachers did not find it easy to adjust to the husband's severe hearing loss resulting from Meniere's Disease. Now for the first time, Robert was forced to look at his wife in order to lipread her. However, because he was not used to 'looking', he often misinterpreted her facial expressions, and misunderstandings resulted. Mary, his wife, recalled a recent encounter:

> "Robert often thinks I'm cross... when I get a worried expression on my face...(This morning) I was just thinking how I was going to answer his question 'what was I going to do today?'...because there was no reason for (him) to flare up...I was really just thinking."

Robert countered,

> "(But look at it from my perspective) ...I was upset because of her reaction...When you've spent forty years able to converse easily and then one goes deaf it's very difficult to adjust to a totally new situation where one needs more facial expression, more patience, and more guess work..."

Robert resented his need to look at his wife to facilitate lipreading. As he was used to doing other things while he talked, he felt a loss of autonomy and control.[39] Not

only did he have to look, he also had to wait which finally triggered the expression of his frustrated feelings.

Thus some couples had more difficulties than others in making the 'face to face' adjustment so that lipreading took place. When this occurs, clinicians need to consider whether or not there exists a fear of intimacy.

The following section will look at how the need to lipread may reveal barriers to intimacy.

LIPREADING STRESS: FEAR OF INTIMACY

Wynne places 'intimacy' as the fifth and most highly developed relational process in his Epigenetic Principle.[40] Other processes in this schema are discussed in Chapter IV and VIII.

Here the focus will be on how intimacy can be a fearful experience for many people.[41] Because of this fear, it is often more comfortable for people to maintain a number of close relationships which are not as demanding as a deeper intimacy might be, for example, with a spouse or a child. Usually experiences from childhood have taught them to adopt this pattern of relating to protect themselves from possible pain or loss.[42]

A fear of intimacy usually has its roots in life experiences and there are four common types of fear: fear of merger, exposure, attack, and abandonment.[43] One couple quite vividly illustrated how these fears operated within a relationship.

Joe, 64, a designer, and Sarah, 48, a lipreading teacher, had been married for eight years and it was the second marriage for both. In certain respects, their relationship had been founded upon their mutual sense of 'loss'[44] and Sarah's unique insight into the hardships of hearing impaired people.

However, a problem which emerged in the research interviews was their difficulty in sitting down so that lip reading could take place. Although Sarah claimed it was Joe who would never sit down, further discussion revealed Sarah also had difficulty surrendering herself to an exchange. Sarah recalled:

> "I was just thinking how I said to Joe, 'stay here!' because otherwise he goes and does things, and I have to wait until he sits down again...(it's) so frustrat(ing) because I can't talk."

Like Robert, Joe revealed his strong resentment in not being able to get on with his work while still talking. Research on gender suggests that this is a specific resentment that is felt by traditionally socialised men who normally would talk and work at the same time. Sarah clarified her position:

> "...I'm very pleased...(Joe is) as active as...(he is)...(it's) bang, bang, crash, crash, and everything. So you know he's around...My point is that I always seem to be the one waiting around for my husband to sit down and listen to me."

Joe replied:

> " Talking about communication from my point of view, Sarah has said that she has to wait while I settle down. I've found it frustrating while Sarah is doing some thing...and I'm sitting down and I want to say something to Sarah. I can't talk to her when she is moving around. Now it's not a question of Sarah not being able to hear, it's I not being able to keep my mind on what I want to say to her when she's got her back to me. Some times I'm the one who has to say, 'sit down!' She's just as bad."

Although Sarah did not understand Joe's point here, she did give him the reassurance he needed at other times. In an earlier interview, Sarah discussed how

they were able to go on short holidays together, sit down face to face over meals, catch up on each other's news, and support each other.

INTERPRETATION: A CASE FOR COUNSELLING?

Although in many ways Joe and Sarah had outgrown problems from their past, their difficulty in sitting down so that lipreading took place suggested that there were still a few unresolved conflicts. From their previous marriages, it was likely that Joe most feared abandonment while Sarah feared the possibility of attack. This would lead to a general fear of intimacy described by Byng-Hall.[45]

On the positive side, Joe and Sarah had learned to live productively with their many differences such as gender, age, religion, personality, sensitivities and deafness as they were now more aware and tolerant. Counselling intervention as discussed further in Chapter XIII, could help this couple be more open about their fears so that they would no longer sabotage their efforts to communicate. And in time their more relaxed attitude would facilitate more cooperative, less fraught interchanges.

Although the four psychosocial dynamics which caused stress in lipreading have been discussed separately, in fact they overlapped in the study. With clients, it would require a number of counselling sessions before clarification of specific lipreading stresses could be made.

The discussion of communication strategies continues with an assessment of the psychosocial factors which influence the art of disclosure.

MANAGEMENT OF THE COMMUNICATION STRATEGY OF DISCLOSURE

A coping strategy which has caused some contention among rehabilitators is that of 'disclosure'. This process takes place when hearing impaired people identify themselves as individuals with the problem of hearing loss.[46] Many clinicians believe that when the hearing impaired person discloses in this way, their act facilitates the process of 'acceptance' of the disability by everyone.[47]

Although this may be a well intentioned conventional view, it is also simplistic. While disclosing encourages hearing impaired people to outgrow 'denial', it can endanger one's sense of autonomy and control.[48] Because we do not live in an ideal world, the act of disclosure in itself cannot ensure that hearing impaired people's needs will receive priority or understanding without continuing negotiation and clarification.

For example, although recently diagnosed Anne had only a mild hearing loss, she was initially determined to keep knowledge of it from anyone who had any authority over her, fearing that it would decrease her credibility as a teacher and researcher. Her attitude appeared to be a pragmatic thoughtful one and did not seem influenced by the psychological mechanism of denial.

Secondly, disclosing to oneself and to others are two different processes although they may coincide for some people. It is likely that gender, age, culture, and personality are social factors operating in this case. The literature suggests that elderly English men, when they become hearing impaired, are particularly vulnerable to isolation, as disclosure generally is not a gender or cultural norm.[49]

Thirdly, admitting a hearing loss to others generally and to significant others specifically are two different processes. Because 'care' is traditionally a bi-product of family life, disclosing a hearing loss within the family circle would be likely to

cause less stress and discomfort than disclosing it to strangers or people connected with one's work, although there are always exceptions.

Lastly, the people in this study suggested that whether or not it is appropriate to disclose, depends upon many social and situational factors, for example race, nationality, gender, class, and cultural values.[50] Specific factors were a) parental attitudes and training; b) gender role expectations; c) immediacy of diagnosis; d) the personality of the speaker and the listener; e) role expectations; f) culture; g) religion; h) concern for others; i) length of acquaintance.

In practice these factors operated in a number of ways. For example, Joe talked at length about the influence of his parents on his disclosure pattern. His mother had denied his hearing loss and wanted him to appear perfect, while his father had 'made nothing of it' to the point where he made little effort to be lipreadable.[51] Joe internalised these attitudes so that at 64 years of age, he was still using a 'pretence' strategy as will be discussed in Chapter VII. It was likely that gender, religious, and age factors also played a part in his thinking.

Conversely, Henry, training for the priesthood, seemed to be well aware of the conventional expectations of specific roles namely being a good guest, patient, student, father etc. However, he had internalised the attitude that being a good Christian meant 'not being of any trouble', and it was very difficult to get him to take responsibility for his need of repetition. Frank, a university professor, had a similar strategy but for slightly different reasons. Since he had only recently been diagnosed as hearing impaired, he still sometimes felt a sense of guilt or shame that he did not hear something. This feeling occasionally prevented him from disclosing his disability and asking for clarification.

Disclosure strategy also seemed to be affected by peoples' personality and profession. For example, Rachel and Robert were extrovert teachers who loved engaging with people. Rachel, a sociology lecturer, freely disclosed to her students when her hearing aid battery ran down, and changed it in front of them. Robert, a

retired religious education department head, went everywhere with his radio microphone and handed his transmitter to others as an aid to lipreading saying:

> "I'm severely hearing impaired. If you'd like to come in the corner to talk to me, fine."

The personality of the listener was mentioned by Frank. He found it difficult to disclose his hearing impairment to colleagues he perceived as impatient since they tended to shout; or students who were excessively shy since it seemed to cause them pain to repeat things when they felt uncertain.

Lastly, nondisclosure, can be related to a genuine concern for others.[52] While many hearing people are able to respond appropriately once they know what the issue is, there are others who are likely to feel stressed when faced with the extra expectations of speaking to a person who has a hearing loss.[53]

In general it seemed to be the case that the disclosure patterns which emerged in this study were partly guided by underlying cultural and religious norms specifically English, Christian, Jewish, American and Nigerian.[54] The hearing impaired people in the study from American, Jewish, and Nigerian backgrounds appeared to be more comfortable with disclosing their hearing loss than people from traditionally English backgrounds.

It emerged that each person in this study was responding to numerous factors which meant that they appeared to feel most comfortable in adopting a selective, thoughtful sometimes intuitive disclosure strategy.

As we have seen, the communication strategies discussed so far have involved extra thought and sharp vision. There will now be a brief discussion of manual strategies specifically British Sign Language.

BRITISH SIGN LANGUAGE

British Sign Language (BSL) is the language of Deaf people in the UK and has been so since there have been reports of those working with Deaf people. By its nature, BSL must be visual at least from the point of view of the receiver. However, it is not a pantomime or gestural code as was formerly thought.[55] It has its own grammatical and semantic system, in the form of signs instead of words. Rather than sounds, there are building blocks in the manual channel. Stokoe, a medievalist and linguist, describes three parameters for American Sign Language (ASL): l) the location of the sign in space, 2) the handshape used in making the sign and 3) and the type of movement made by the hand or hands.[56] Scholars of BSL add a fourth component which is the orientation of the hand relative to the body. In addition there are further components. Recently recognised building blocks of signs are facial expressions, lip patterns, signer's eye gaze, and body posture specifically the shoulders and the head.[57] These components are then recombined in limited ways. This is similar to the spoken word which is composed of a sequence of units called phonemes, arranged in role-governed structures. Thus Sign and spoken languages are now believed to be more alike than previously thought, since from the point of view of internal analysis, there is no basis for treating them differently.[58]

In this study, three eighths of the people had contact with British Sign Language. Two people, Arthur in BSL and Christine in ASL, were fluent. Arthur used it as the main mode of communication in the home with his wife Gwen. Christine used voice and Sign together as total communication. Sam, Joy, Henry, Robert and Barbara had all taken courses. However, it often appeared that taking a BSL course was a symbolic act of acceptance as described in Chapter XI rather than an acquired usable skill.

Some people in the study did have a marked ambivalence towards using BSL. There seemed to be the implicit fear that learning would lower their status in some way which had already been lowered in acquiring a hearing loss.

SIGNED ENGLISH AND SIGN SUPPORTING ENGLISH

Other communication strategies which are used were Signed English and Signed Supporting English. Signed English is a form of visible English. It used the sign vocabulary of British Sign Language, often with additions to show English word endings, tenses etc. in English word order. Sign Supporting English is similar, but uses finger spelling or lipreading rather than added signs to complete words in English word order.[59]

Sam, Joe, and Barbara mentioned their use of Sign Supporting English. It appeared to be used when the frustration level began to rise after repetition had failed. Signed English did not seem to have the stigma value for the people in this study that BSL had acquired. The last communication strategy found in this study was the use of the voice.

VOICE

All sixteen people in the study used their voices although one couple, Arthur and Gwen, used BSL, and did not speak in the home unless guests were present. Sam, Barbara, Grace, and Anthony expressed concerns about the loudness or the quality of their voices. These four people were concerned about the volume of their voices in different situations and would sometimes need to establish this usually by asking their partners. Grace, had been told by her ex-husband that her voice was horrible, and laugh was ghastly. Her hope was that the cochlear implant that had just been given to her would change that. One husband, Mike, expressed quite the opposite. He said with obvious delight that his wife's (Joy's) voice had not changed in the twenty-five years that she had been deaf (see Chapter VIII).

SUMMARY

An analysis of the communication strategies used by the people participating in this study together with a more detailed analysis of the difficulties that presented

themselves when lipreading took place, suggested that lipreading stress was associated with encountering strangers, stress with unlipreadable children, stress for men generally who felt threatened or provoked by the intimacy required in the act of 'looking' in order to lipread, stress in being forced to change long established marital communication patterns, and stress resulting when 'looking' requirements and marital intimacy generally were experienced as frightening because of past failed marriages.

Other psychosocial factors which emerged for possible exploration in a future lipreading study are the interaction of peoples' cultural background, personality, experience, and attitudes, towards those with whom they interact. In considering culture in the broad sense or 'the way of life' of people with acquired hearing loss, this chapter argues that special attention be given to non-verbal cues which are given and received through the process of 'looking'. It is of particular significance that couples, with or without the presence of hearing impairment, who 'look' at each other when they speak, are likely to have higher quality relationships than those who do not.

This chapter argues that taking responsibility for lipreading is an exercise in patience and courage on the part of both the hearing and hearing impaired partners. Although feelings of irritation, frustration, and fatigue maybe experienced on occasion, the more positive feelings of affection, respect and connectedness tend to prevail if a positive emotional 'fit' existed before the hearing loss was acquired.

The use of disclosure as a communication strategy is explored. It is argued that there are many individual factors which influence the appropriateness of disclosure with a given person at a given time namely culture, religion, gender, the personality of the speaker and the listener, age, concern for others, attitude of parents, and duration of the relationship. Consequently, to view the refusal to disclose a hearing loss as a sign of 'denial' and failure to adjust is a simplistic and reductionist interpretation.

Although the rehabilitation theme continues in Chapter XIII, the focus of the study now turns to the couples themselves. The next chapter will look at how the hearing impairment was managed when the couple first met and began to consider each other as potential marriage partners.

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[56] ibid., pp.78-79.

[57] See Kyle, J. and Woll, B. (1989) Sign Language (Cambridge: Cambridge University Press).

[58]Padden, C. and Humphries, T. (1988) Deaf in America (London: Allen Lane) pp. 60-61.

[59]Miles, D. (1988) British Sign Language (London: BBC Books) p.111.

CHAPTER VII THE PERCEPTION OF THE IMPACT OF HEARING IMPAIRMENT ON THE DEVELOPMENT OF COUPLE RELATIONSHIPS WHEN ONE PARTNER HAS A SEVERE /PROFOUND HEARING LOSS

INTRODUCTION

As we have seen, ten out of the eleven couples interviewed were legally married. Like all contemporary heterosexual couples, they had to struggle with the tensions created by the major paradox of marriage today: the relationship is thought to be all important, and yet couples continue to seek the security of the institution.[1]

The perspective of family in this study is that of psychosocial constructionism.[2] Attention is focused on what people say about the 'familial' in their lives namely family discourse; and how people practised family description and constructed family meaning. To speak of being 'family' is not only to use the term to describe a set of relationships, but also to convey the idea that the relationships under consideration are trusting and giving. Despite negative views which some scholars have about the family, the 'trust and giving' referred to here is being seen in a positive light.[3]

The eleven couples interviewed in this study were divided into two groups. The first group consists of five couples where one spouse was already severely/profoundly hearing impaired at the time of their first meeting. The remaining six couples married each other with no awareness that deafness would strike one of them further into the marriage. Consequently the deaf element in the marriage was not a part of the original commitment, but was encountered after the marriage was well established.

The focus of this chapter will be on this first group of five couples. The literature as well as common sense suggests that where a severe/profound hearing loss is present in the midst of a heterosexual relationship, it is likely to stir up specific issues, alongside more general themes common to all committed intimate relationships.

These will be discussed along with the highly personal manner which these couples psychosocially constructed the meaning of 'deafness as a difference'. In doing so, the couples in this study focused on 'differences' as part of an anthropological/cultural model rather than as a medical model.[4] This point is further clarified in Chapter XIV and illustrated in Chart I.

All couples pass through developmental stages as their relationship evolves and deepens.[5] The analysis shows that the five couples in this chapter passed through three specific developmental stages. Before considering the evolution of these stages in greater detail, some general contextual material on partner selection is presented.

COUPLE CHOICE

The literature suggests that it is necessary to be aware of both conscious and unconscious factors involved in mate selection as the relationship between a man and a woman is so complex.[6] Some of the theories presented to explain mate selection are the following: l) homogamy, the tendency for like to marry like as in similar religious, cultural and educational backgrounds;[7] 2) heterogamy, the tendency for men and women to choose marriage partners who are unlike themselves in the same factors;[8] 3) endogamy, the requirement that a person selects a marriage partner from within the tribe, community, social class etc.;[9] 4) the concept of need-complementarity, the characteristic where the individual consciously and unconsciously seeks out a mate to complement his own personality type;[10] 5) attachment theory[11] and marital interaction theory,[12] as discussed in Chapter II.

The analysis now continues with the focus on the three developmental stages which have emerged in this study alongside shared perceptions of 'deafness as a difference'.

STAGE 1

Both the hearing and hearing impaired individuals need to clarify their attitudes and feelings about the deafness factor as questions and concerns emerge in their growing intimacy if the encounter is to be sustained and an enduring relationship formed. In addition their more general attitudes to differences and problems require testing and mutual assessment. This is because there are bound to be differences other than the deafness itself which will need to be addressed. Conversely, if a lack of agreement is found between the potential partners on the fundamental issue of deafness, their relationship is likely to flounder at this early stage. If some agreement is reached, this dialogue is the beginning of the process of finding and shaping 'like-mindedness' in life more generally.[13]

SIGNS AND SYMBOLS OF REASSURANCE AND COMPLIANCE WITH SPECIAL NEEDS

The hearing partner must convey reassurance to the hearing impaired partner that 'deafness as a difference' within their relationship is seen by them as potentially manageable. Consequently, it is not denied or seen in an unduly negative light. The use of mutually understood symbols and/or signs conveys this reassurance. There must also be an awareness and compliance with 'special needs'. For example, for some the ability to establish a quick and easy rapport is important.[14] Arthur, a prelingually deaf husband and student, recalled meeting his hearing wife, Gwen:

> "...there was never...a serious problem...(where) communication was concerned...I think her range of Signs was (widening at the time we met); she was fairly proficient. It's partly her unconscious desire to get more involved with Deaf people."

Gwen agreed:

"I found (Arthur) very easy to talk to and he seemed to be able to put up with my awful Signing...(It) did help that there was easy communication straight away. If we had both had to struggle, perhaps it would not have gone any further."

Gwen's use of BSL and openness to further learning reassured Arthur that Gwen was sincere in her wish to have a long term involvement with Deaf people. As Harris argues:

"...sign language...use acts as a marker of willingness to conform to the core philosophical belief-that sign language is 'natural' to Deaf people. Stemming from this, my data shows that there are assertions of Deaf Clubs being 'natural sign language environments'; that BSL is many Deaf people's 'first' language and that sign language use promotes 'mental health' in Deaf People."[15]

Henry, a prelingually severely deaf theological student found reassurance in his capacity to respond almost immediately to the initiatives of his future wife, Kay.

"...(Kay and I) just seemed to be able to communicate with each other...we were very open with each other,..I think I had more hang-ups than Kay..!"

Some couples seemed to feel safer when they felt a force or person beyond themselves had brought them together. Kay talked about 'God's will' while Joe talked of 'fate'. Joe also mentioned his doctor's encouragement to attend the lipreading class where he met his future wife, Sarah. Sarah, in turn, told how her tutor encouraged her to approach Joe.

"...when we were teaching lipreading, Joe was...(a pupil). It astounded me (how attractive he was)... The teacher told us that there was a man (in the class who was tragically separated from his sons and it was him)...I thought 'Poor man', and she told us to go and talk to him."

For Sarah, a combination of feelings and events swept her along into Joe's presence. Joe, in turn, was delighted by her attention and they discovered they shared common interests. Joe was also reassured by Sarah's dedication to teaching lipreading. He recalled:

> "...one evening when I got (to the lipreading class),..(Sarah) came up to me and said, 'How about having (the) coffee (which I had suggested earlier) with two of (my) colleagues?' I replied, 'No way, only you...as it's enough to have to understand you, without...try(ing) to follow the other two people as well in a cafe'. That was her first lesson aside from all the other lessons!"

As Sarah complied with Joe's 'special needs' showing her sensitivity, Joe dared risk further involvement. Barbara, a severely deaf wife and mother, described a similar incident. She had known Ben for a number of years since they both were in the legal profession. She recounted how a severe bout of influenza helped her to resolve her doubts:

> "I had 'flu...I suddenly went (totally) deaf for three weeks - ghastly...and I remember noticing that I could lipread Ben even though I was totally deaf...so in terms of verbal communication I would say we were pretty good."

Ben's ability to be relaxed in the face of the formidable qualities of total deafness was the reassuring sign that Barbara needed. Ben confirmed her point:

> "Barbara is very good at lip reading. I don't really think we have to make a great deal of effort, to be honest."

These remarks repeat the familiar theme that what is crucial is the ease of communication between the partners, regardless of the physical obstacle of

deafness. This theme lends credibility to marital interaction theory when it supports the psychological factor of unconscious 'couple fit'.[16]

The fifth couple, Julia, a textile designer and Sam a profoundly deaf computer programmer were different from the other four couples in that they resisted formal marriage. Sam experienced reassurance initially about his deafness when Julia agreed to share his 'special need' of living a self sufficient life style. Later when they had to give up their dream for practical reasons, the commitment had transferred to their relationship.

In this way the hearing partners communicated that 'deafness as a difference' could be managed without undue strain or sacrifice. In fact many of the hearing partners in this study had encountered deafness in their past and/or were in the midst of acquiring a professional helper career in the hearing impaired field. This meant that an initial concern and interest in deafness had already taken root for them quite apart from their encounters with future spouses.

Marital researchers also suggest more generally that couple formation is aided by fortuitous events such as the individual attitudes to marriage at a particular time within a climate of events and circumstances. The next examples will show how these events were in operation and the resulting impact.[17]

FORTUITOUS CIRCUMSTANCES: HENRY AND KAY

Fortuitous circumstances were much in evidence in the meeting of Kay, a 35 year old trained teacher who was establishing a second career in the Church, and her severely hearing impaired future husband, Henry. Kay recalled:

> "...I had been feeling that to be a woman in the Ministry who was single..was...a disadvantage,..that if I had the authority of a husband,.. I would feel happier going into the public sort of ministry that the Church of England Ministry is,..but...I (wasn't) actually looking for a husband..."

She recalled her first encounter with Henry at college:

> "...I had no idea that Henry was deaf...except in the beginning evening service when prayers were held and everybody gathered together...the principal said something about sign language...and he said it to Henry...and it stuck in my mind..."

Later when Kay and Henry happened to have coffee together, Kay asked Henry about the principal's remark and Henry explained about his deafness. Kay recalled thinking that it seemed incredible that Henry was deaf as he could communicate so well. She then decided as it did not seem to be a communication problem to Henry, why should it be for her. Kay recalled:

> "...(perhaps) we didn't really know each other very well, but I ...felt that (Henry) was a person who came from a similar background...to myself as regards family, and that we had quite a lot of things in common...we weren't totally opposite in anything except we were the opposite sex!"

Henry, on the other hand, was intrigued with Kay's "nothing unusual is happening" approach as described by Emerson.[18] It reflected his own attitude and seemed more balanced than that of other women in his life. Together, Henry and Kay psychosocially constructed 'deafness as a difference' to mean an 'insignificant factor' or that everything could proceed as normal within the marriage as long as adjustments were made for 'lipreadability'.

In practice this meant that Henry had to divide himself in two: the hearing part of him was involved with his family, his studies and his work; the deaf part was to be connected with the Ministry to the Deaf which he planned to develop once he was ordained. Although not the ideal way to cope with differences as the distancing by one partner from unconsciously perceived negative attributes of the other, more often than not results in increased frustration and loneliness for that partner, Kay

and Henry agreed implicitly on this method and it was maintained. Privately, Henry acknowledged:

> "...(Kay) assumes she knows...(what it is like to be deaf)."

Although Kay talked knowledgeably about Henry's deafness and resulting pain, her actual behaviour suggested that she had largely separated herself from it and there was little real room for his disability in the marriage. This attitude was revealed in her feelings of resentment when Henry didn't wear his hearing aids all the time. Although a very gifted person in many ways, a certain insecurity and lack of patience made it difficult for Kay to allow Henry the extra time and space he needed to bring his 'deafness as a difference' and accompanying feelings of isolation further into the marriage. At the same time, Henry colluded with Kay's attitude by not disclosing more of his true feelings.[19]

This assessment was noted along with the fact that Henry and Kay, at the time of the interviews, were experiencing a very demanding period in their lives which might have given a slightly distorted picture. The following is an example of another couple who chose to manage the deafness factor in their relationship in an entirely different way, but the themes of reassurance and fortuitous circumstances are the same.

FORTUITOUS CIRCUMSTANCES: ARTHUR AND GWEN

Gwen, an infant teacher, also met her future husband, Arthur, at college.

> "...I had been working (and)...I (was) on my own for about a year, saying things like, 'I'm never going to get married,..I'm going to be a single woman with a career'...so I certainly wasn't looking around for somebody...but (Arthur) came along, and I suppose I turned it all on its head."

Gwen felt that her interest in Deaf people had occurred long before she met Arthur. This was borne out in her commitment to learn BSL and in the preparation of a special paper on Deaf/hearing integration. Arthur, like Henry, felt that here was a different sort of woman. However, the issue for Arthur with women was not the quality of sympathy, but the quality of commitment. Arthur recalled:

> " It wasn't just a...new hobby...with Gwen,..she took it seriously. In many ways it made an impression on me."

Gwen's affirming attitude contrasted sharply with Kay's as Arthur's did with Henry's. This may be because Arthur and Gwen were younger, and they had both found strength from involvement in Deaf culture. Henry had only just started this process, and Kay was not interested.

While Arthur's deeper feelings about his own deafness were ambivalent due to his experiences of injustice in the world, he publically proclaimed a positive attitude towards the deafness of Deaf people generally. This position is what Harris has conceptualised as the Deaf Construction of Deafness.[20] For the purposes of this thesis, Arthur and Gwen's joint perception was seen as 'deafness as a difference' being 'respectable and ok'. For Gwen there was also a sub-text. She recalled:

> "...when (Arthur) told me his family was Deaf,..particularly his...father...and grandfather,..I knew then that I had to start thinking seriously of what I was getting into...I had to decide whether (hereditary deafness) was something I could cope with... and I decided it was."

Although on the surface Gwen and Arthur presented a more united front than Kay and Henry, there were still many differences in outlook which needed to be addressed. Arthur remembered:

> " I think it's more to do with (the) perception of how things should be done, (for example,..Gwen's) perception of the world is due to having always been

in a hearing environment. My parents are Deaf, and sometimes when...(Gwen and I) argue, these different perceptions are raised to the surface."

Arthur's acknowledgement of different perceptions was the first indication of what Padden and Humphries have identified as ' a different centre' often experienced by members of the Deaf community.[21]

Apart from the question of signs, symbols and compliance with mutual 'special needs', there is the question of whether or not couples are going to have children.[22] Partners who were not parents appeared to allow more space for the integration of 'deafness as a difference' in to their couple relationship as the following example illustrates.

FORTUITOUS CIRCUMSTANCES: JULIA AND SAM

Julia met Sam at a mutual friend's house when at university. She admitted that Sam's profound deafness made little impact on her since she was so caught up with her own concerns. Certainly the fact that he made nothing of it himself, and that he did not wear a hearing aid, might have made her initial insensitivity to his disability more complete. Fortuitous circumstances existed in that she found herself in a academic course which she disliked intensely and the place where she lived was cold. This contrasted with her enjoyment of being with Sam who was sympathetic and his room was nice and warm.

The stress which Sam's deafness was to cause only gradually came to the surface. In this way Sam and Julia psychosocially constructed 'deafness as a difference' as a 'stress' factor within their relationship. This stress factor appeared in both their private relationship and in their interactions with the outside world. Julia and Sam explored the problem together. Julia began:

"...(Sometimes)...you've misunderstood what I have said, and I get angry because you get angry, and then I make it worse because I will say, 'What do you think I said?' which is awful really... because it kind of reinforces that you didn't understand in the first place."

Neither Sam nor Julia made any attempt to dodge the difficulties which they experienced. Anyone could get 'the wrong end of the stick' from time to time, but it was more difficult when one's partner was profoundly deaf, and the other simultaneously profoundly impatient! Sam replied with understanding:

" Sometimes (people) just don't have the patience...or communication (skill)...it's more (about) understanding...the other person... When two people live together, they are bound to rub each other up the wrong way now and again."

Sam knew that 'differences' could be managed constructively. Julia occasionally forgot that she must slow down her speech as Sam was deaf, and he was deeply sensitive especially where she was concerned. Julia blamed her unpredictable moods for her occasional incapacity to respond to Sam's 'special needs'. Her insecure background and job often made her the demanding one. This was particularly true when there was a crisis. She recalled:

"...if there's a problem,..if something has to be arranged or discussed in a hurry,..it's difficult to translate that quickly to Sam...I think it is because he is deaf and not because of his personality..."

In such circumstances, Julia experienced Sam's deafness as a 'brick wall' and a stress factor within their relationship. Sam's deafness could also cause stress with strangers in that it provoked rudeness. Sarah recalled how even a so called friend had made the stupid quip:

"It must be strange for Sam to have sex with you because he can't hear your ecstasy."

Julia forgave people for such intrusiveness, but it also made her feel uncomfortable and sad.

What was distinctive about Sam and Julia's relationship was its complete lack of pretentiousness. Moreover, they were both very open about the negative impact of deafness on their lives, and made no attempt to glamourise or trivialise it. Julia deeply experienced the 'stress' along with Sam although she knew she occasionally provoked it. This meant that Sam was not left to handle it alone unless it was his choice to do so. Sam expressed his appreciation of Julia's enduring support by saying from the heart, "She gave me back my youth".

Sam, understandably, felt enormous gratitude towards Julia. In most, although not all situations, she was able to prevent the 'stressful' side of 'deafness as a difference' from tainting their enjoyment of life and of each other. A similar sense of gratitude was experienced by Joe in his relationship with Sarah as may be seen in the following example.

FORTUITOUS CIRCUMSTANCES: SARAH AND JOE

Joe, a designer, was divorced after a twenty year marriage and was the father of two sons. He recalled:

"In my first marriage, the woman, although she was encouraging, wasn't understanding enough about the problem of communication... so much so that (her attitude) was passed on to my sons..."

Joe blamed his first wife for not helping his sons to understand the implications of his deafness for effective communication. Sarah, his new wife, added reflectively:

"I suppose your biggest 'if only' is that there had been someone who was able to explain to your wife what your problem was so that your wife could explain to your boys..."

Sarah thought that sympathetic counselling might have saved Joe's marriage. Because his disability had been largely denied by Joe's first family, it was critically important that Sarah and Joe shared a common understanding of it in this second attempt at matrimony. They both found reassurance in Sarah's profession as a lipreading teacher seeing it as a guarantee that the meaning of 'deafness as a difference' within their relationship would be psychosocially constructed as a 'communication problem'. Although Sarah obviously felt that the extra effort required to communicate with Joe was worthwhile, she did experience real deficits, especially the loss of spontaneous domestic chat. Sarah related:

"...in the kitchen (I) am sitting at the table...literally wait(ing) until Joe has finished moving around...I am not complaining because he is usually...helping,..(but) you can't...say silly things like 'We've run out of milk' when your head's in the fridge...there's no point."

Sarah pointed to what has been conceptualised as the ETTA factor. This was the Effort, Time, Thought and Attention required by Sarah so that Joe could lipread her. The concept of ETTA draws attention to the fact that some hearing people must think carefully about the requirements for lipreading. This is because what they feel to be their natural and normal way of speaking runs counter to these requirements.[23] Specifically they have to think whether or not at a particular point in time they have the energy to put into the Effort, Time, Thought and Attention needed to engage with a lipreading hearing impaired person.[24] Sarah explained that more time was required when communicating with hearing impaired people because "...you've got to be more graphic...to use a lot more visual signs..."

Sarah's previous marriage had alerted her to the fact that communication as well as love was needed to make a marriage work.[25] But Sam's hearing impairment made

the situation even more complex. She explained how talking to a hearing and hearing impaired person differed for her:

> "...well 'normal' means fast speedy conversation, not thinking about whether it's lipreadable or audible, (or) if the light's on your face,..(or) you talk like this (putting your hand over your mouth)...(Normal conversation means) talking while you're eating your cheese sandwich, while you're reading your paper...that's all absolutely normal..."

The ETTA factor is about having the energy for the Effort, Time, Thought, and Attention required to help a hearing impaired person take their rightful place in both formal and informal conversations. The provision of access to conversations follows the same principle as the provision of a ramp for wheel chair users so that they may enter and leave buildings. This concept will be reintroduced in Chapter VIII in the context of 'caring'. Sarah also mentioned how inhibiting Joe's deafness could be when they were in bed. She recalled:

> "...when Joe takes his hearing aids out at night, he's gone... absolutely gone...I don't feel alone, but I always think it will become quite a big effort to become intimate and I find that quite difficult because I like to express things..."

Sarah's experience echoed Debbie Kisor's as they both saw the inability to hear as an obstacle to intimate communication.[26] Their attitudes may be contrasted to that of hearing people who are the sons and daughters of Deaf parents.[27] Although there is much variation, many of them had learned in their childhoods that darkness and silence did not necessarily preclude communication especially that conveyed through forms of touch.

The psychosocial constructions of 'deafness as a difference' have been discussed for four of the five couples mentioned in this chapter. For the fifth couple, Barbara and

Ben, 'deafness as a difference' psychosocially constructed as a 'frustration' was not conceptualised until after the children were born (see Chapters VIII and IX).

The integration of 'deafness as a difference' varied in degree with each marriage and was examined with care, since sometimes what couples said was not what they did.[28]

At the next stage, couples continued to work on their mutual psychosocial construction of 'deafness as a difference', but other concerns took priority.

STAGE II

SIGNIFICANT OTHERS

Stage-II began when the couples told 'significant others' of their attachment and of the definite possibility of future commitment. The percentage of cohabiting couples in the study appeared to reflect the national norm of just over half of courting couples.[29] Of the five couples discussed in this chapter, three cohabited from three months to one year before they married. One couple married a little more quickly than intended as the wife was pregnant; and the fifth couple, where both partners were training for the ministry, had a traditional wedding ceremony.

Meeting one's future in-laws is a stage that most newly formed couples find daunting, but the risks taken by partners when one is hearing and the other is hearing impaired are greater.[30] This is because couples are drawn from two groups, sociologically speaking, 'outsiders' and 'insiders', and may be perceived as deviant and unacceptable by either group.[31]

Arthur and Gwen were the only couple in the study to explain this developmental stage in detail, as they had married a relatively short period before the time of interviewing. Arthur remembered:

" (Gwen's) parents...were very encouraging...(In the past when) I had been taken home to a girl's parents,..a few of them had not been very welcoming, because I am deaf, and especially with a history of deafness in the family."

Gwen explained her understanding of her parents' attitude:

"...Because I had learnt Sign before I met Arthur,...they knew I was mixing with Deaf people for nearly a year...If I had suddenly out of the blue brought this deaf man home, that might have been a bit of a shock."

Gwen's parents were exceptional as reflected in their attempt to learn BSL. Gwen's mother, Beatrice, recalled her feelings about Arthur and his deafness when they first met:

" (Arthur's) deafness was never an...obstacle...(he) was welcomed in, just as any boyfriend (of Gwen's) would have been welcomed in, and we made allowances..."

Beatrice acknowledged a sense of enrichment:

"(Arthur's) coming into our family has opened a completely new world for us and we have learned a great deal from Judy and Paul, his parents..."

Beatrice thought their welcoming attitude might be connected to the tradition of 'hospitality' which she and her husband, Andrew, had experienced growing up on the Isle of Lewis. Arthur also introduced Gwen to his parents during this stage, as they lived near her first teaching position, but he gave <u>his</u> parents less preparation. Gwen recounted:

"...(He) introduced me as 'this is Gwen: can she come and live with you in September?' which his mother accepted...I had his room...it was useful for me because it improved my Signing..."

Arthur's assurance of his parent's cooperation under such circumstances is perhaps indicative of the depth of trust which existed in this Deaf family. What occurred next may be interpreted as Arthur and Gwen's version of a cultural exchange programme with romantic undertones.

At this time in their courtship, Arthur lived in Gwen's home in Reading so that he could finish his college course and Gwen lived in Arthur's home in Southampton so she could begin her teaching job. Although there were practical reasons for this arrangement, it provided Gwen and Arthur with an excellent opportunity to get to know the family culture in which the other partner had grown up.[32] It was also a way of coming to terms with differences in a very direct open manner from the beginning. Gwen and Arthur discussed their experiences. Gwen began:

> "... Your Mom's house is much more structured than mine...I had to be tidier...I found from time to time I was called to the door... (and) I would be the interpreter...it was difficult for me to work out how much to get involved in that sort of thing...(As for loss of sound), I missed the radio in the mornings dreadfully because we in Reading get up to Radio 4,..and it (really) pushes you out the door...(In the end) I got used to it."

Gwen's brief experience with Arthur's parents reflected descriptions of what it is like growing up as a hearing child with Deaf parents.[33] Like them she had to struggle with mixed feelings about silence and the responsibility of interpretation. Arthur gave his account:

> "...(living with Gwen's parents) affected them more than it affected me...(as I had already become) familiar (with hearing people)...the only adjustment I had to make was to adapt to... household rules...since two households are never alike."

In-laws were reported as being important at this stage by two other couples. Ben did not refer to Barbara's severe deafness when he first introduced her to his parents as he wished them to meet Barbara, 'the person' not Barbara the 'deaf girl'. Although Ben's attitude was commendable up to a point, Barbara had been deaf a long time. There was the question as to why it had to be 'either/or' rather than both Barbara, the person and Barbara, the deaf girl. The unconscious message conveyed was that Barbara the deaf girl was someone repulsive who belonged outside family boundaries. Full integration could not take place because apparently neither Barbara, Ben, or his parents could cope with the mixed feelings caused by acknowledging that Barbara was both normal and different, hearing and deaf.[34]

Julia acknowledged that her parents expressed considerable concern after hearing of her intention to live with Sam. After visiting them, her relations made further patronising comments such as 'Sam is much better now'. Although Julia felt that her relatives saw Sam as some kind of performing monkey because of his deafness, she may have been a little oversensitive on Sam's behalf. For example, profoundly deaf Arthur used the same phrase, 'she is much better now', when referring to his hearing mother-in-law! While his remark obviously came from his 'different centre',[35] it also seemed to be a genuine affirmation of his mother in-law's efforts to widen her horizons.

MANAGEMENT OF INTERPERSONAL POWER

The couple's feelings about the developing power balance was another area of the relationship examined at this stage. Much is written in the sociological literature about power in interpersonal relationships.[36] Interpersonal power here refers to the ability to achieve a desired end through influence. In other words, power enters a relationship when people (i.e., powerholders) have the ability to achieve ends by influencing others. The literature suggests a number of interpersonal power models.[37] French and Raven list six different types of power bases which people use in their interpersonal relations: reward, coercive, referent, legitimate, expert and informational. Traditionally men are viewed as using a greater number of power

bases than women, but this is changing. For example, Scanzoni and Scanzoni identify two marriage models: a) the corporation type of marriage where the husband acts the role of chief executive with the wife as junior partner; b) the egalitarian marriage where there is relative equality between the spouses' rights and privileges.[38] They both have full time careers and share in all decisions.

At this stage power problems connected with 'deafness as a difference' must seem manageable or the relationship will flounder. Arthur and Gwen reflected on this point. Arthur said:

> "...one important characteristic (of our relationship) is that it's a partnership of equals, rather than a partnership where one partner dominates the other...we have our particular strengths and weaknesses, And if I have a weakness, (Gwen) has a strength which compensates, and vice versa..."

Undoubtedly, Arthur and Gwen shared a vision of a relationship which could be interdependent[39] rather than the carer/cared for, dependent/independent model.[40] He continued:

> "I am not sure whether we are two opposites. It's more like a jigsaw puzzle- it so happens that we fitted together..."

The concept of need-complementarity is in operation in Gwen and Arthur's relationship and a certain equilibrium is felt.[41] Arthur reflected on 'deafness as a difference' as it affected their relationship:

> " I see (the fact that Gwen is hearing) as a positive characteristic,..in...that every day things like using the telephone are made much easier. It's true,..that I wasn't looking for a hearing person...(On the other hand, making) crucial decisions...can be done...(quickly) on the phone,..and (in) this way I am grateful I married a hearing person."

Arthur took care to be discriminating and by the use of understatement, he inferred that hearing people were not superior just because they were hearing, as his Deaf parents supposed.[42] Gwen continued the theme confirming the concept of need - complementarity.

> "We have had different experiences, but we can put those together. I had been through college, and Arthur had not...so that made me all the more determined to help him,..not through any great sympathy,..I just thought, 'this is something that we've got to tackle...'."

Gwen obviously liked the challenge that being married to Arthur provided. However, Arthur was unsure of his career leanings and was frightened to confide his doubts to Gwen. He recalled:

> "I had this irrational fear of telling...(Gwen) that I now wanted to be an accountant and not a social worker. (Perhaps)...if I told her, our whole relationship...would suffer...or she might call off the wedding,..so I kept quiet about it..."

The fact that Arthur should have doubted the strength of Gwen's commitment to him was understandable given the long history of hearing people's neglect of Deaf people's welfare.[43] Gwen expressed her exasperation at Arthur's inability to trust her:

> "I...don't mind what he does. I will support him in anything as long as I know in which direction we are going,..it was (his) not telling me that I didn't like..."

Gwen had the potential to be a powerful healer as she not only symbolised 'woman as helpmate', she also brought the hope of equality with hearing people. In other words, some of the rejections and disappointments of the past at the hands of women and hearing people could now be transformed and perhaps transcended through the acceptance and respect which Arthur experienced in his relationship

with Gwen. There were moments, however, when Gwen increased Arthur's anxiety such as when she refused to accept his proposal of marriage until he had a job, and when she was half an hour late for their wedding.

Henry had similar thoughts about his relationship with Kay. He recalled:

> "...being a deaf person (with a hearing) partner...at the beginning of the marriage, I used to feel quite insecure when we got in to an area of tension. I always felt because she was 'hearing', she had the upper hand; but because of the way Kay is as a person, she's allowed me to go through the experience and mature..."

Henry was very appreciative of the support which Kay gave him. However, the real issue between the couples generally was not one of 'equality' in the abstract, but of how the hearing spouses with their command of the spoken word actually managed their linguistic power with their hearing impaired partners.[44]

An exchange between Arthur and Gwen typified what could occur. They were discussing what kind of education their unborn child ought to have. Eventually Arthur became fed up with Gwen's dogmatic tone and said:

> "You never...gave me a chance (to explain myself properly)...I felt (you were) almost accusing...me (of not caring)...about (our) child's emotional development, or their ability to think."

Although Arthur was careful to be respectful of Gwen and her expert professional teacher power base, he felt hurt by her apparent disregard for his opinion in his roles as her husband and the future father of their children.[45] Gwen clarified her attitude:

"I'm not saying you don't care, but that I worry that the type of school you want, won't care....You...are ready to find out about these schools, I've already formed my opinion."

While Arthur could fight back, it was not without a certain amount of anguish. While Gwen was inflexible here, Arthur could be equally so especially on the topic of sign language and the past treatment of Deaf people.

In the majority of relationships in this study, hearing partners gradually learned to manage their linguistic power for they valued an egalitarian relationship with their hearing impaired partners. However, that linguistic power was not necessarily the prerogative of the hearing partner. For example, Robert, deafened as he approached retirement from Meniere's Disease, was more articulate than his hearing wife, Mary. Rachel, who suffered from otosclerosis, spoke more forcefully than her hearing husband, Richard.

When some of these issues had begun to be addressed, the couple gradually moved on to Stage III where they became more self consciously 'a couple'.

STAGE III

The themes of Stages I and II continue in to this stage. There are new issues as the relationship moves into the more serious stage of commitment. The couples begin to settle down and to become more aware of what it uniquely means to be 'a couple', and to respect that meaning. They begin to explore the various structures surrounding them which can help take the stressful edge off a marriage relationship where 'deafness as a difference' is being integrated. Routines are established, social networks evaluated and developed, and new leisure/work patterns explored. The couples learn that stress and crises will continue as in all marriages, and that they are manageable as patterns of support begin to emerge and warning signs seen.

ISSUES FACED BY THE EMERGING COUPLE

THE EMERGING COUPLE: EXPERIENCING STRESS

As stress and crisis are an inevitable part of marital and family life,[46] additional resources will be required for the integration of the meaning of 'deafness as a difference' into the marriage relationship.

As we have seen, the meaning of Sam's profound deafness was psychosocially constructed as 'stressful'. It provoked rudeness in others and enormous frustration in Julia especially in times of crisis. An area of 'stress' for Sarah and Joe was 'disclosure' when they were out shopping as they had very different attitudes about it. Joe recalled:

> "I wanted to get a pair of...binoculars...We found a nice shop...(and) and I...(went) in and...(started) talking to the young (sales)man...But I...(didn't) tell him I'm hard of hearing..."

As a traditionally socialised male, Joe was reluctant to disclose as he wished to avoid the condescending attitudes his past disclosures had provoked. Sarah found his behaviour frustrating as she explained:

> "But it's interesting as an observer how...relieved people are when they know someone (is) hard of hearing,.. rather than having to spend...(time) trying to explain something and thinking, (when the communication breaks down that) it's them(selves), or thinking they're facing a stupid man..."

Sarah's 'common sense' view was also understandable. She confided:

> "...Now...when...(Joe) is having an interaction in a shop, I move away...(otherwise) they always end up talking to me..."

Because of their differing attitudes, Sarah had learned that it was best to withdraw completely from the situation. Gwen talked about the stress she experienced during her first year of marriage to Arthur:

> "The doctor said, 'Oh you have just got married, go and get on with it' sort of thing...And then it passed over...I had just finished my first year of teaching...so it was all a bit much all in one go..."

Eventually Gwen and Arthur discovered that an established routine helped cut down their anxiety. Feelings of stress were also attached to interpreting tasks (See Chapter VIII). Here Gwen talked about making telephone calls for Arthur.

> "...I get exasperated in having to make phone calls for him. I hate it...I don't know why."

Arthur agreed:

> "This (situation) upsets me (too), because if my hearing was OK, I'd be doing the phoning, and it upsets me that other people seem reluctant to phone (on my behalf)."

This switch in natural talent made them both feel extremely uncomfortable within their relationship. Thus stress accumulated when spouses were forced to behave in a manner counter to their natural inclinations.

Arthur and Gwen had already begun to work out a more appropriate solution in the context of ordering meals when eating out. Gwen explained:

> "...(Arthur) used to rely on me...when we went to a restaurant. I was giving the order...and people would look at him as if he were peculiar or something...there's nothing wrong with his speech...I make him do it now and it's fine...but you didn't like it, did you?"

Arthur replied:

> "I hated it...I felt silly, self conscious...but it's not so bad now."

Arthur was prepared to overcome his anxiety to please Gwen. She in turn was sensitive to Arthur's 'situational dependence', sensing when to act, and when to encourage him to risk possible embarrassment.

THE EMERGING COUPLE: A MUTUAL VISION OF INTERDEPENDENCE AND COMMITMENT

Mansfield and Collard maintain that despite present diversity in contemporary social life, there are two basic issues at the heart of becoming and remaining a couple: commitment and interdependence.[47] Commitment may be seen as a belief that stabilises the behaviour of couples in that they have faith in their long term relationship.[48] Other scholars are more blunt and see commitment as perseverance stemming from a balance between a 'have to' (cost) and 'want to' (reward).[49]

The concept of interdependence as a measure of a marital relationship is relatively new. Cohen[50] writes that it is rather like a bargain...between two adequate, self-sufficient, successfully dependent adults, namely that the giving goes both ways. In terms of coping with dependency needs, the equilibrium (achieved) must be flexible enough to allow for shifts in situations of stress.

If two people are to be defined as 'a couple', there needs to be a level of interdependence in at least some of the following dimensions: sexual, economic, emotional, practical and social. Sarah and Joe had a very clear conception of what they could give and take from a marriage relationship. Sarah explained:

"...when I got married (to Joe), I said I'm not going to do any more housework, and no more Sunday lunches...a waste of time. Someone else can do it who likes to see things clean..."

This didn't worry Joe as he was delighted to have found a partner who understood his 'special needs', who was so hospitable and caring, and who had experienced loss herself without being devastated by it. He said:

"I went through a rotten experience being deaf, Sarah also went through a rotten experience and we've met and disproved how difficult it is for a deaf person to get on with a hearing person..."

Joe and Sarah built a relationship around physical attraction, common interests, mutual experiences of 'loss' and continuing support. This formed the basis of the commitment and interdependence that satisfied them. The nature of commitment emerged with another couple, Julia and Sam, as they explored the possibility of Sam having a cochlear implant operation. Julia said:

"...but if Sam had (the operation), and that's what he wanted,.. I would be very pleased for him...Sam supports me and I support him so I would support whatever he wanted to do...unless he wanted to run off with somebody else..."

Julia's slightly frivolous remark did not belie her devotion. Arthur also struggled to articulate his feelings about his and Gwen's relationship:

"...in 18 months the equality of the bond (between us) has changed...I think we are much more dependent on each other. I'd have said we don't need anybody else,..yes, (we've become) a couple instead of two people...we have become an entity..."

Gwen had a more earthy perspective for she replied:

"Well we argue less, but again that's... because we are coping better with all the stress...when we first got married...we just argued all the time..."

Perhaps quarrelling may be part of the ritual of courting since the 'lover's tiff' is such a universal phenomenon.[51]

Arthur and Gwen, as they became more committed and involved with each other, discovered that some old ties had loosened. They went on to consider the specific nature of their relationships with closer relations and friends.

THE EMERGING COUPLE: INITIAL SOCIAL NETWORK FORMATION

As two individuals become a couple, they begin to make sense of the social world around them.[52] Families of origin appeared to play an important role in initial social network formation. Sarah and Joe were proud of the links which had been maintained with Sarah's family. Barbara and Ben mentioned that they had 'invested' a lot in their families of origin.

Julia and Sam had mixed feelings about their families, but were glad they were there. Henry and Kay had found strength in the feeling that they were both from the same type of middle class background. Besides family, Gwen was aware that her relationship with her best friend, Charity, had taken on a new dimension after she had decided to marry Arthur. She recalled:

"My best friend...(of) ten years,..Charity,..she is single... She thinks (Arthur's) wonderful, but if (we get together), it's Charity and I, (who) go off together...we leave (Arthur behind),..because...he'd be bored to death. She and I are like another couple...a different sort of couple."

Gwen was able to retreat into a more familiar same sex hearing relationship with a single friend. Having gained strength, she was able to cope with the demands of

her marriage. Arthur, on the other hand, did not require such a relationship which he interpreted as a gender difference between them as supported in the literature.[53]

THE EMERGING COUPLE: MAKING NEW FRIENDS

Couples who have normalised 'deafness as a difference' in their relationships are likely to puzzle people generally. Their social world is complex with potential for both enrichment and rejection.

Prelingually deaf Barbara, illustrated this point with her realistic assessment of the difficulties. She felt that busy hearing people were often wary of her as they did not know what burdens friendship with her would bring. Because of this, she often took social initiatives as she believed that this strategy helped to counteract the possibility that she would be seen as a 'wounded bird'. Although her hearing husband, Ben, was aware of Barbara's struggle, his role was usually to support from the sidelines.

In fact, the women in this study, whether deaf or hearing, appeared to feel responsible for initiating new friendships. Gwen reflected:

> "I don't...find it easy to make (new) friends...I'm lucky that I've...acquired enough over the years...twice we went to the pub with all these young teachers, and they just ignored...(Arthur). Well I won't put up with that...he comes first,..and if they don't want to know him then I don't want to know them."

Arthur responded:

> "If people start to be funny about Gwen, then I would shut them out...the only important relationship that matters is ours."

Gwen and Arthur were concerned about the possibility of encountering 'stigma' from members of their own cultural group directed towards their partner.[54] They

knew that their commitment to each other was primary and that they were not to be wedged apart in this way. They found it easier to make acquaintances and friends in the local branch of an organisation called 'The Breakthrough Trust'. It encouraged hearing and Deaf people to meet and contained a number of couples like themselves. Gwen recalled making one new friend using the time honoured method of 'secret sharing':[55]

> "The closest friend I've made is a colleague at work,..she is old enough to be my mother...I've told her about the baby, I haven't told anybody else...she's very good to me..."

As a bicultural couple, Gwen and Arthur began to discover where they were and were not welcome. Their attitudes appeared the reverse of what might be expected. Although Arthur was Deaf, it was Gwen who appeared to have the greater fear of rejection and the lower self esteem. She acknowledged how her advocacy role with Deaf people, specifically with Arthur and his family, helped her to overcome her fears.

> " Oh yes, I could do anything if it's for...(Arthur) or his Mum...But if it's for myself, I won't do it (like) asking for things in shops...(I'd rather) go out empty-handed. (Their need) gives me something to hide behind."

Gwen had stumbled on the circular nature of help in that there was an interdependence not just between herself and Arthur and his family, but between Deaf and hearing people more generally.[56] Social networks will be discussed in greater detail in Chapter XI and XII.

SUMMARY

In this chapter, an attempt has been made to look carefully at the five partners in this study who committed themselves to each other when one partner was already severely/profoundly hearing impaired. This suggested that the deafness was unconsciously if not consciously part of the attraction. It was found that these relationships developed over three stages.

Stage I began when the hearing partners reassured their hearing impaired partners that their 'special needs' were manageable. Partners also had to mutually psychosocially construct the meaning of 'deafness as a difference'. In other words, an anthropological/ cultural perspective rather than a medical model was used. This highly personal joint perception was then integrated into their growing relationship. For example, the five couples psychosocially constructed deafness to have five different meanings: 'an insignificant factor', 'respectable and ok', a 'communication problem', 'a stress factor', and 'a frustration'. These constructions appeared to occur unconsciously because of the emotional 'fit' between the partners, but were consciously acknowledged in the couples' professed ability to talk easily and openly with each other. At this stage, some hearing partners became aware of the ETTA factor (Effort, Thought, Time and Attention), or the requirements needed for their hearing impaired partner to lip read. Other partners, for example Ben, had sufficiently integrated these requirements so they were unconscious.

In Stage II, the partners took their infant relationship to 'significant others'. There was the expectation that family members might be threatened. This was found to be the case with some families, but not with others. During that time, couples also evaluated the interpersonal power balance in their relationship. The majority of couples described themselves implicitly if not explicitly as being egalitarian, committed, and interdependent. The issue of 'dependence' was found to be a situational phenomenon within a continuing reciprocal relationship.

Stage III began as couples became more serious in their intentions, often seeking a formal as well as informal expression of their commitment. Various structures developed around them which helped to balance the formidable side of 'deafness as a difference' when integrated into a marriage relationship. As the couples felt more secure and less tense with their shared perception of 'deafness as a difference', they were able to bring some order into their family responsibilities and friendships. These couples needed very specific listening and communicating skills because of the enormous scope for misunderstanding. The very nature of 'deafness as a difference' in their marriages meant that the people in this study came into contact sooner than other couples with areas of conflict. In most cases, there was sufficient love, wisdom, and communication skill to manage them.

Since similar perspectives and experiences could not be assumed, a process of like-mindedness had to be nurtured. The problems of such a marriage were by nature the same as those of an ordinary marriage, but they were experienced earlier, had greater intensity and had more significant consequences. The distinctiveness necessary at the heart of such a relationship was what made it special. In making allowances at the very beginning of the relationship for ways the other person was different, pleasure for both partners was created as they became aware of the variety in their relationship. It enabled a husband or wife to say everyday, "He/she never ceased to surprise me".[57]

Let us now consider the impact of hearing impairment on the continuing relationship. Some of the couples in this chapter will be revisited and couples where hearing impairment first appeared some years in to the marriage will be examined.

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CHAPTER VIII THE PERCEPTION OF THE IMPACT OF HEARING IMPAIRMENT ON THE COUPLE DURING THEIR CONTINUING RELATIONSHIP

INTRODUCTION

The focus in the last chapter was on the formulation or early courtship stages of couples where one partner was hearing and the other was hearing impaired. These same five couples will now be re-examined in the light of their continuing relationship along with six couples whose hearing impairment did not occur until their marriages were well established. Consequently none of the partners in this latter group had entered marriage expecting to need or to provide any extra care as a result of a disability, such as deafness. In this chapter we will, therefore, look closely at how the sudden traumatic 'loss' of hearing of one partner within an ongoing committed relationship affected that relationship.

The fact that the disability requiring adjustment did not occur until the marriage was well established has parallels with the experiences of couples discussed by Parker.[1] However, it is argued that the behaviour of the six couples in this chapter fits the anthropological/cultural model[2] in much the same way as emerged in Chapter VII, rather than a medical model. This is because the disabled partner did not require traditional forms of 'tending care'[3] as emerged in Parker's study. For these mutual perceptions to develop, a new 'contract' had to be implicitly negotiated by the couples which incorporated the realities of the degree, type and nature of hearing impairment along with methods for coping with it.

In order to understand how the couples negotiated or renegotiated their contracts,[4] the concept of 'care' needs to be assessed along with the sociological context from which it develops. 'Care' on an intuitive level is described as the provision of help, support, and protection for vulnerable and dependent members of society. The exact nature of the type of help given is often left unclear.[5] A strong distinction is

made between 'care' as concern about people generally and the actual looking after or the 'tending' of more or less dependent people.

Bulmer suggests that 'care' may be seen on a spectrum of three types, with each type being further removed from the recipient of the care.[6] Firstly, there is the physical 'tending care' just described. Secondly, there is material and psychological support which does not involve physical contact, such as the telephone support given from kin and friends to an elderly person. Lastly, there is a more generalised concern about the welfare of others which may or may not lead to the other two types of help.

There are, of course, connections between the help which hearing impaired people receive from their partner and traditional concepts of 'care' to be interpreted as 'the roles' adopted by the hearing partner on behalf of the hearing impaired partner as the situation required. However, there are a number of difficulties in making this connection. Firstly, the help provided by the able bodied partner or the hearing spouse for the hearing impaired spouse, rarely caused the distress[7] mentioned in the Parker study; although on occasion in certain specific situations, the findings suggest that stress, frustration, and resentment occurred. In acknowledging this, it is understood that stress, frustration, and resentment occur in every close relationship as they are natural responses in coming to grips with human differences. Many would argue that the institution of marriage itself brings about negative feelings to an extreme degree as partially evidenced by the high divorce rate.[8] Secondly, 'care' was never provided on an all consuming daily basis, but only occasionally when needed for specific situations. Thirdly, the hearing impaired member of every couple was employed in a paid or volunteer capacity, and able to function in the public sphere completely independently of their partner. In contrast to much of the evidence presented elsewhere,[9] which implies that such relationships cannot be reciprocal[10] in the long term, a loving rapport on both sides is the most significant and striking features of most of the study couples. However, initially, it is not always evident how the eight people with the more

severe/profound losses in the study returned the social access support that was so obviously and generously given.

It is argued that the majority of couples in the study presented aspects of the 'ideal' companionate marriage[11] as described by Berger and Kellner[12] in that partners were close enough to psychosocially construct reality together. In other words, the partners articulated their mutual perceptions of reality, and thus together created a joint understanding or construction of the present reality and their place within it.[13] A similar idea has been applied to the way in which families' construct the reality around them.[14]

But unlike the Berger and Kellner model, couples in this study also presented more realistic aspects of their relationship[15] resulting from a deep understanding of the demands and constraints of society, two careers, children, and the disability itself. Therefore, the type of marriage which emerged contained a balance of realistic and idealistic aspects reflecting some understanding of both the institutional and relational components of marriage similar to the couples interviewed by Mansfield and Collard.[16]

Moreover, the majority of couples interviewed may be typified as functioning or optimally functioning marital/family systems in the way in which they managed the crisis of becoming deaf, whether suddenly or gradually. This conclusion is based upon the observed presence in the relationship of some degree of cohesion, adaptability and an enabling communication. Family researchers, Olson and McCubbin, believe that these three dimensions are the most important in facilitating the continuing constructive development of family life.[17]

The best illustration in the study of these dimensions at work was the relationship of Anthony and Clare who were in the midst of adjusting to Anthony's sudden deafness. Substantial a loss as the deafness was, it was only one of three major losses at this time as racism and migration were also being experienced.

All three experiences were related in that they involved a loss or change of identity and then eventually some sort of resolution and integration of the past and the present. With Anthony and Clare, this task was threefold: coming to terms with present reality meant some kind of integration of the Nigerian 'white' hearing world they left behind, with the English, Black, Deaf world they were now experiencing.[18]

There will also be a discussion of how the couples studied managed more peripheral and yet paradoxically not unimportant aspects of their relationship, for example domestic sociability, distance management, leisure patterns, and the breakdown of intimacy.

Finally, because marriage is a relational system, this study adopts the 'Epigenetic Principle'[19] for examining the ways in which hearing loss affects couples. According to this developmental principle, there are five relational processes. The first and second sections of this chapter will be an analysis of the first relational process of attachment/caregiving. The last section will be an analysis of the remaining three relational processes of 'communication', 'problem solving', and 'mutuality'. Intimacy, the most developed relational problem, has been discussed in Chapter VI.

FIRST RELATIONAL PROCESS: ATTACHMENT AND CAREGIVING

An understanding of attachment/caregiving processes is largely drawn from John Bowlby's theory of 'attachment and loss' (see Chapter II). The fact that attachment behaviour is less obvious when the affectional bonds are felt to be secure, does not mean that the underlying affectional bonds are less. Ainsworth comments that "in a good marriage each partner on occasion plays the role of the stronger and wiser figure for the other, so that each derives security and comfort from the other, as well as wishing to be with the other and protesting against actual or threatened separation".[20]

On the basis of this theory, it might be expected that the married hearing impaired people in the study would be strongly attached to their hearing partners. It might also be assumed that the attachment would be stronger when the hearing loss was greater. This was suggested by some of the remarks made. Henry, a severely hearing impaired theological student acknowledged:

> "...Kay is... a very strong person and has a deep Christian commitment (and) faith...a very moral person...she gives me a tremendous amount of strength and security to enable me to come up..."

Although Kay was not as generous with her praise, she was especially thankful for Henry's presence during specific moments such as when she gave birth to their second child.

> "Yes, I'm afraid I was very much physically hanging on to Henry as keeping me in reality (during labour); and as he was there, everything would be all right eventually."

Kay lacked appreciation of how her vulnerability in this instance nourished the reciprocity in her relationship with Henry. Reciprocity was displayed more openly by Joe and Sarah. Joe recalled:

> "...Sarah has done a tremendous amount for me, as she is doing for a lot of people...she has brought new life into mine."

Sarah tempered her enthusiasm with realism:

> "...the last ten years...have been the happiest in my life...I don't say that I don't get fed up 'coz Joe knows I do,.. (but) now we overcome it by talking about it...and we never have nasty in-depth rows."

As emerged in Chapter VII, Sarah was more than happy to cope with what they had mutually perceived as their 'communication problem' or the meaning of Joe's deafness, if in exchange, Joe was prepared to talk things through in contrast to the rowing pattern she had encountered in past failed relationships.

Deafened Sam and his hearing partner, Julia, were the first to admit that they did have rows. However, they appeared to resemble lover's tiffs in that it was safe to row without causing permanent damage. She explained her enormous regard for Sam.

> "...(Sam)...is the victim of ...(the GP who prescribed the drug that deafened him), who made a gross error...it's only Sam's personality and his strength of character which has helped him keep on an even keel,..through going deaf and living with it."

Julian was openly admiring of Sam's stoic tenacity and refusal to become embittered when he became the victim of a doctor's ignorance. Sam, in turn, talked about his enjoyment of Julia's company:

> "When we lived in Norfolk, we were together the whole day and the whole evening...we got on all right...What I would like...(is to own) a small...farm...if we both worked on that, we would see each other all day, but we wouldn't be in each other's pockets."

The above quotations reveal the reciprocity of attachment found generally within the relationships of the couples in this study. Two deafened spouses stood out in that their praise of their hearing spouses was more restrained. Joy remarked offhandedly:

> "Well, of course I've had my husband to help me through; and we've carried on more or less like we've always done."

Joy's remarks suggested that her enforced social dependency on Mike had caused her to value him less, a phenomenon noted by Hetu, Jones and Getty.[21] Nigerian Anthony talked in a teasing tone about his hearing wife, Clare.

> "She is a good girl...not as good as before...she's changed...she's no more good...I'm joking...there are many qualities...the way she talks, the way she takes life,...the company of goodness..."

The ambivalent tone of these remarks are better understood by a closer look at Anthony and Clare's cultural context. Anthony was likely to be reflecting the strong 'macho' element in Nigerian, specifically Ibo culture. His words also revealed his frustration and displeasure at his dependence on Clare for 'interpretation' in social situations, which he had previously easily controlled with his enormous charm and warmth. Such feelings are not restricted to deafened African men since they are well documented as experienced in the UK.[22]

Clare didn't take offence at Anthony's disparaging tone because she knew his life was difficult and that he had compensating qualities for his occasional irritability especially his genuinely responsible and caring attitude towards his family. Unlike some wives,[23] Clare was happily aware of her good fortune in being married to such a man.

Anthony, himself, believed that his deafness had made him more responsible and more serious. Nevertheless, his seriousness was tempered with humour. Clare recalled:

> "Yes, Anthony had a good sense of humour...a crazy sense of humour...it makes (our relationship fun). (It helps to) laugh it off..."

The focus now moves to the more general area of domestic sociability.

DOMESTIC SOCIABILITY

Domestic sociability is defined in this study as the spontaneous expressive remarks, sometimes humorous, to do with the practical, social and current events of the day. This type of exchange is not especially profound, but is often intrinsically gratifying in that it conveys belonging;[24] and is seen as a cohesive force in relationships especially among women.[25] These exchanges could be on the level where most marital conversation takes place; or could be the first rung of a deeper relational process, for example, communication or a type of intimacy.[26]

From earlier discussions, Sarah and Joe will be remembered for psychosocially constructing Joe's severe deafness as a 'communication problem'. Throughout the interviews, Sarah frequently recalled her feelings of 'loss' in conversing spontaneously with Joe. She pointed out that Joe's deafness, and a number of his more formidable mannerisms, inhibited her desire to launch both serious discussions as well as more inconsequential ones. She recalled:

> "Well, it stops you talking...(and) making remarks about what's in the papers and (you) think, 'Oh, I cannot be bothered;..but I haven't got the energy sometimes..."

While Joe also shared a sense of 'loss', it seemed to be a more general feeling about life. He explained:

> "I quite like to forget...that I can't live a (completely) normal life...although I keep on saying, 'Let's keep it normal'...it's not (always) possible."

While Sarah sometimes felt socially deprived, these feelings lessened with time as confirmed by Parker.[27] The feelings of sadness lessened as the ETTA (EFFORT, THOUGHT, TIME, and ATTENTION) factor required for effective communication with Joe was integrated.[28]

Other hearing spouses mentioned similar feelings with regard to loss of spontaneity. Mary (68) and Robert (70) deafened from Menieres, were both retired school teachers. Mary remarked:

> "...Sometimes (while watching televison), I miss sharing things... Although...(we're) watching it together,..you can't have television and talking."

Mike agreed, but referred specifically to the use of subtitles. He said:

> "...While the subtitling is on,..I can't talk to (Joy)...because if she looks at me (so she can lipread), she's missed what's on the television. So you tend to lose out on spontaneity...I can't have a joke or anything like that while a programme's on..."

For Julia, partner of deafened Sam, there was also a feeling of 'loss' even though she had never actually known Sam when he was hearing. She felt that many of her witty, sarcastic, and subtle comments fell flat or were missed. This did not mean they did not appreciate humour together, but it was more visual than oral.

A common pattern emerged in reviewing the couples discussed here. Hearing women married to deaf or deafened men gave something extra, 'ETTA', to the relationship because they felt something 'special' was given in return. As career women, they particularly appreciated the support and encouragement provided by responsible and caring husbands. Mike and Joy revealed a different pattern which will be discussed in the next section.

The underlying theme of attachment and caregiving will continue as the focus shifts to the specific roles of the hearing partner.

ADDITIONAL CARING ROLES OF THE HEARING PARTNER

Roles which the hearing partner on occasion carried for the hearing impaired partners were buffer, monitor, interpreter, mediator, prompter, advocate, and editor. Their implementation was seen to create a more expressive intensity between the partners than might normally be expected within traditional reserved English middle class couples.[29] Frustration was sometimes experienced when the hearing impaired partner felt that their hearing partner was not conducting these roles exactly right. There could also be a certain 'social dependency'[30] in such relationships at times. This had occasionally resulted in resentment on the part of the hearing impaired spouse and stress on the part of the hearing spouse.

In focusing on these roles, it needs to be restated that the relationship was reciprocal overall. As may be detected in the comments of most partners throughout the study, there was much deep mutual admiration and respect between them. This meant that these roles were taken on within the context of a mutually interdependent and committed relationship. The additional roles may also be seen to reflect appropriate degrees of 'adaptability'[31] found in well optimally functioning family systems.[32]

The discussion on roles begins with Joy, aged 60, who at the age of 35 was suddenly deafened by Meningitis. She said:

> "...(Mike) thinks he (understands and) I think he tries to; but,..sometimes he doesn't seen to realise (how left out I feel),..(especially) when we are with other people."

Despite Mike fitting the criteria for a 'high marital adjustment husband',[33] interpreting on behalf of Joy was full of pitfalls as she described:

"Sometimes he will realise that I'm not 'in'...the conversation...and he will bring me in. But of course, I suppose.., he gets interested in the conversation and will forget about me."

The literature suggests that women make better interpreters than men. The 'forgetting' attitude mentioned here may go hand in hand with the general flavour of male sociability and bonhomie.[34] On the other hand, there are very real complexities as Joy illustrated:

"It is difficult when there are several people...to bring you into the conversation...(Mike) will say 'We are talking about something...' and I will say 'Oh yes,' and make a remark. And then, of course, a hearing person will pick that up (and I won't be able to hear as the subject changes)...If there are only three, it's not too bad. But more than that...(is very frustrating)."

Mike tried his best in this difficult situation.[35] However, like BSL interpreters, it was likely that he and other spouses of severe/profound hearing impaired people would suffer from 'role strain' on occasion.

Hearing Clare, who had previously interpreted for her Nigerian grandmother, found it much more demanding to interpret for her husband, Anthony. She explained:

"It is...(a hard) job being an interpreter...I'm not a very patient person...so there is a lot of strain...especially when there's a lively discussion going on,..it's difficult... to take part and try to make (Anthony) follow what is being said;..by the time you've tried telling him what they have said, they've moved on...I feel guilty when I see him looking lost, and he asks what's going on."

Pauline Ashley made a similar observation about her efforts in helping her husband Jack, the former Labour Member of Parliament, now in the House of Lords.[36] She recalled:

> "On social occasions I may be acting as both a participant and an interpreter. It is only too easy to fulfill just one of the roles. I am rather a single-minded person, and, if I get absorbed in conversation, tend to become oblivious of what is going on around me. Fortunately, I have learned to participate in one conversation while simultaneously being aware of another. In this way I can help Jack quickly should it be necessary."

Although Pauline Ashley implied the possibility of mastering the art of effective social interpreting in time, it seemed doubtful that the stressful element ever really disappears. Sainsbury suggests some specific reasons for this within a marital as opposed to a professional context; for example, hearing spouses cannot walk away from the problem, they are involved emotionally, they have no official training, they are likely to reproach themselves and be reproached by their spouses for not interpreting quickly or precisely enough, and they don't get paid for it.[37]

Interpretation is seen to be easier if it is shared by other guests in a social situation. For example, Mike mentioned how it worked with friends:

> "The husband, because he has a beard, can't talk to Joy directly,..so it will either be myself that inteprets or this other person's wife, Joy's friend..so there is always some explanation from one or the other of us."

Argyle suggests that women generally are particularly sensitive to nonverbal cues.[38] However, there were occasions when a social evening meant Sarah had additional, sometimes incongruent roles to play. She recalled a particularly embarrassing accident:

"On Saturday evening we had friends here for dinner; and I was bringing through the trolley (from the kitchen). And...(Joe) asked me a question,..and...because I automatically have to turn around to answer (him), the trolley hit the side of the door because I wasn't watching where I was going,..and unfortunately the cream fell off the trolley...It...(wasn't) possible (to be in both roles at once). I...(couldn't say, 'Wait a minute' or not answer because we had friends here (and that would be rude)..."

In this instance, Sarah's role strain[39] resulted from the conflict between being a 'hostess' and a 'caring wife'.[40]

Along with interpreting, two wives of hearing impaired men also edited their own speech or other people's on behalf of their husbands. However, the reasons for doing this varied. Julia explained her view:

"...But there is no way...(I)... have the energy sometimes to...'precis', ..so that the conversation is...short,..meaningful, and to the point. I mean you can't talk about what we call 'the price of tomatoes' forever...so you need a lot of (mental) energy."

Joe responded:

"I have no patience with people (who talk about) 'the price of tomatoes'. Please get to the point. Oh no, (I'm not a chatterer) A to B finish."

Patience was an issue for both Joe and Sarah, but in opposite activities. While Joe might have chatted more to please Sarah, like many men, he felt more comfortable in conversations which 'reported' rather than feminine 'rapport' talk. He added:

"(I do communicate socially) but I find, I suppose because I am deaf, I don't like (conversations to be) so long...that one has to think 'Now what exactly is that person saying?"

Although Joe connected his preferred conversational style with his deafness, it may be a collection of social factors, for example, gender, personality, class, intelligence. Julia also edited for her partner, Sam, but more in social gatherings than in dyadic conversations. She recalled:

> "I...edit...for speed (when interpreting)...so...complicated sentences...are...simplified which can mean that...(Sam) may lose some of the meaning. Also I may 'interpret' for other people... sometimes I say things that they have not said to try to get the meaning (across) more quickly..."

Despite Julia's inaccuracies, Sam managed to enter the spirit of these exchanges, doing his best with his own lipreading skills. Robert (70) had a similar strategy when attending the biannual international meeting in France of people with his surname. Mary described what occurred:

> "(Robert) starts conversations...so I come in...as interpreter,..(but) Robert's French is...much better than mine...(so) we try to work as a team...I try and understand somebody...then I tell him, and then he will...reply, or he will say the first thing and I will hear the answer, and then tell him...it's sort of (a) three way (process)."

Interpreting, editing, and prompting are tasks which are often linked with the telephone, an instrument which lipreading skills cannot master. Julia was happy to do Sam's phone work as she was a declared 'phone addict'. She sometimes prompted Sam to speak:

> "This is your Mum...say 'hello'...and he says 'Hello'."

Sarah regretted doing telephone tasks which she knew Sam preferred, for example, ringing up garages when they wanted a car. Gwen explained how she attempted to approach telephone interpreting from a practical perspective.

> "If we were both deaf,..(Arthur) would find another hearing person to do (the telephoning)...it's like marrying someone who is good with cars, you never have to worry about the garage bills..."

Other issues connected with the use of the telephone were 'social decision making' and 'privacy'. An example of the latter was when Mike became 'carried away' in accepting or inititating social invitations on the phone. Joy sometimes resented being told after a conversation was completed that 'so and so' was coming over or the reverse. Joy also felt a sense of loss when Mike answered the phone to her personal friends. She explained:

> "...my friends call and of course Mike has to answer...it's not like having a (proper) telephone conversation...you can't have any secrets...yes, I do miss the telephone...it's just (that) other people don't like writing...I don't belong to the RNID telephone exchange. It's very useful if you've got a businesss...but for ordinary chat, it hardly seems worth it...no privacy."

Mike, like Julia, obviously enjoyed using the telephone so he was happy with his interpreter role. Joy, however, regretted her inability to use the phone as it represented a double loss: an inability to monitor their social life and to retain autonomy over intimate friendships.[42]

Clare related difficulties about the 'timing' and 'style' of phone calls for Anthony. She complained:

> "...(Anthony) asks me to phone a friend...and all he wants me to do is deliver the message...and drop the phone...I've got to say 'Hello, How do you do?..How are you getting on?.."

Because Anthony was a recently deafened extrovert man, his inability to make his own phone calls was particularly frustrating. His frustration was compounded by Clare's refusal to make business-like phone calls. Clare continued:

> "(Also when) he wants me to make a 'phone call, it (must be) immediately...He wants me to drop everything."

This complaint was echoed by Gwen and suggested that for an extrovert male, delayed phone calls were difficult regardless of how long they have been deaf. Thus the complex nature of telephone interpreting stood out as causing more stress and conflict than any other role accepted by the hearing spouse. In this specific situation, it was Anthony who had to adjust, but not without a tinge of resentment. He said:

> "...if I have to get someone to ... make a telephone call, the people...(I) work with in my course, they do it better and with more willingness than...(my wife, Clare)..."

However, Anthony was adamant that he and Clare never stored up resentment about their differing attitudes. When discussing their marriage more generally, he talked about how they had learned to negotiate. He said:

> "Myself and my wife...we are both individuals who don't keep (resentments) in the mind for long...I will only say that...life continues again...we go to bed friendly..."

As it emerged, Anthony and Clare were involved in a massive emotional and cultural adjustment, a result not only of Anthony's sudden deafness, but also of the losses involved with their migration to England. Both losses imposed at least a temporary discrepancy between inner and outer worlds, which had to be realigned if they were to adapt and survive with any degree of physical and mental health.[43]

Mike and Joy, in contrast, were from the same London suburb, but they shared with Anthony and Clare a similar orientation about marriage. Mike remembered:

> "We've always done things together... we've each got money...it doesn't matter who spends it...it's ours...not mine (nor) Joy's...so whatever we've got belongs to both of us."

If Mike and Joy shared the prizes of life, they also shared the burdens. Unsurprisingly, it emerged that they had psychosocially constructed the meaning of 'deafness as a difference' in their marriage to be a 'shared burden'. Although Mike may have lacked understanding on the emotional level of the experience of deafness,[44] he was alongside Joy on the intellectual and practical levels. For example, he studied all aspects of Joy's original illness and was knowledgeable about the technical aspects of her cochlear implant. Furthermore, Mike supported Joy through a difficult 'tribunal' which occurred when she was unfairly dismissed from her job in the school kitchens. He also developed a specialised 'buffer' function which the literature calls 'stigma management' when they were on holiday.[45]

The buffer function was used with strangers, but also with members of the family. Although Sarah described herself as being 'a buffer', the role of 'mediator' is perhaps a more accurate description of her behaviour. She recalled:

> "If it wasn't for me being a buffer (mediator) and saying to Joe 'This is what (my grandsons) did say'; or saying to the boys, 'This is what Grandpa heard', we would be in terrible trouble."

Gwen's mother, Beatrice, also had a mediator role. She recalled:

> "...(Being accepting of the difficulties presented by Arthur and Gwen's relationship) is not...always easy. There are times when I could

scream...but I have coached myself...to be (the) person in the family who (tries to keep the peace)..."

Anthony's mother had held a similar mediating role in Clare and Anthony's life, but she had been left behind in Nigeria. This meant that they were left to their own devices in the continuing work of sorting out the meaning of Anthony's deafness and the other losses in their lives.

The next section will focus on the three couples in the study who were suddenly deafened after their marriages began, and the extra pressures on their relationships which resulted.

LIFE FOR THE NEWLY DEAFENED AND THEIR SPOUSES

People experiencing a sudden profound or total loss are subject to an instant disruption of their daily lives often accompanied by a period of hospitalisation.[46] This disruption along with the inability to hear is likely to cause traumatic stress and disorientation.

In July 1983 Anthony sustained near total deafness resulting from drug toxicity. He was 31 years old, four years into his marriage with Clare and the father of three young children. The event of his deafness resulted in a major domestic upheaval and crisis. In order for a comprehensive rehabilitation programme to be implemented, Anthony and Clare not only had to move house, they also had to migrate to England from Nigeria where there were no rehabilitation facilities for adults.

Clare reflected that she only gradually comprehended how Anthony's deafness impinged on their lives:

"...(Anthony) was deaf for so many years until one day he was at home, and I wanted to phone him from work and I suddenly realised if I phoned, he

wouldn't hear...it took me some time to make (the connection in my mind)."

All aspects of communication had to be examined. Anthony was also prepared to acknowledge the problematic side of deafness especially regarding his retraining. He wrote:

"...I have to learn all my facts by reading them. A lecture of one hour can cover the facts in a textbook, but it takes me a week to read (the same book)...But because of my interest and God given ability, I (am able) to work hard,..(and) keep abreast with hearing colleagues."

One of Anthony and Clare's major resources was their couple relationship. Because they were both Nigerian, they could act as psychosocial buffers, protecting each other from too sharp a discrepancy between inner and outer worlds.[47] In an alien environment, their culture was embodied by and in each other as well as in the Nigerian relations and friends in their social network. In this they contrasted with another couple in the study, American Rachel and British Richard. Much distress was caused in this relationship because the British spouse was seen to embody rather than buffer the foreignness of the environment.

Clare and Anthony were also aware that simply coping wasn't enough. They had to be openly positive in their outlook if they wished for the patronage and interest of white English hearing people; and, if they wished to keep the good will of their Nigerian medical friends. Therefore, they chose to perceive Anthony's deafness as a 'blessing but sometimes problematic'. This was because it had triggered the realisation of their dream of migrating to England so that Anthony could retrain as a pathologist. Formerly the move had been blocked by Anthony's medical superiors in Nigeria. This positive attitude of 'acceptance' came naturally within the context of their strong Christian faith. Clare explained:

"...(Anthony's deafness is not) a (big) problem with us...because our African or Christian philosophy is different,..it does not look at deafness as...a stumbling block to achieving objectives in life,..in fact deafness has brought us more blessings than anything else..."

While Clare tended to see Anthony's deafness in spiritual terms, Anthony's metaphors suggested a brave doctor/soldier self image. He said:

"I never took deafness lying down. I was still aiming at the top. But many or most deaf people tend to become withdrawn...so it discourages even the kindest helpers...(as dependency is feared)...In my own case, I was succeeding...(everything) I touched turned to gold!...so my helpers stuck by me."

Anthony backed his conscientiousness and enthusiasm with shrewd common sense. In the next section, caring roles will be revisited in the context of marriage where there is a deafened partner

CARING ROLES REVISITED

Although this mostly positive public account was sincere as well as shrewd, Anthony and Clare admitted that some problems connected with Anthony's deafness were difficult.[48] At one point Clare appeared to recapitulate by calling Anthony's deafness 'the biggest problem we have ever had', a reflection of her ambivalence as she struggled with her own sense of 'loss' and isolation,[49] specifically in her role of interpreter and monitor of Anthony's progress. It was obvious that Clare felt completely unprepared for these roles and that it had been forced upon her by circumstances. Although Clare was happy to be living in the UK, she and Anthony suffered from culture shock. Clare discussed how she prompted Anthony to speak more clearly, not only because he was deaf, but also because he was Nigerian.

"...I have developed (the habit) unconsciously (of asking Anthony to clarify what he says)...because some of the phrases he uses while they might be clear to a Nigerian, they're not so clear to a white person...I tell him to explain more..."

While Clare discovered she had intellectual and spiritual resources to help Anthony, she also found support at the Link Centre for Deafened People in Eastbourne. She recalled:

" ...(The course) showed us...the problems that Deaf people face which we had been hearing (about), but didn't understand. They gave a talk about tinnitus,.. they taught us about finger spelling,..lipreading,..but the most useful talk was the technique of communication,..skills you need to do to help deaf persons communicate better..."

Anthony also spoke highly of the course, especially the practical and career advice given, and meeting other deafened people. He recalled:

" ...you discover that there are so many other people in your condition, you don't feel so bad again."

Although the LINK course was a valuable experience, it was, nevertheless, limited. Clare and Anthony were expected to get on with the process of integrating Anthony's deafness into their daily lives which resulted in some difficult moments. Voice control was a particular concern especially in a noisy environment. Clare spoke to Anthony:

"...Sometimes when we have friends (over) and you are...(talking excitedly),..you (start) shouting...And sometimes (your) voice goes low, and (I)...have to strain...myself to hear...(It may be) the TV's (on) too loud and that's why (I)...can't hear...If ...(I) tell (you...your voice is) too low,..(you'd) think... (I'm criticising you unjustly)."

Anthony acknowledged the truth of Clare's analysis:

> "Sometimes I take...(Clare's monitoring) honestly, and sometimes I feel offended...so I find it difficult."

Anthony's medical training had inadvertently prepared him for some of the problems he experienced. Clare's monitoring role was a very delicate matter for which he felt less prepared. Noise monitoring also took place in Julia and Sam's relationship. While generally a quieter person than Julia, Sam reflected:

> "I think perhaps I'm a noisy person as well. (Julia) can hear anything: Bang!, Bang!, Bang! When I eat...my jaw makes a cracking noise...so I've had to...make adjustments...because it drives (Julia)) crazy!"

Sam's awareness illustrated how people who do not hear are able to take responsibility for the irritating noises that they sometimes make. In contrast, Anthony demanded Clare's help in monitoring his extraneous noises even though he could no longer hear them. He explained:

> "I am a very sensitive person when it comes to noise. I don't like noise... anywhere...There are little noises I make which I don't know I'm making...I usually find that when I eat I make a noise..."

Although Clare did not share Anthony's sensitivity towards noise, She knew he needed to be followed in his efforts to form a synthesis of his hearing and deaf selves.[50] Clare recalled:

> "...sometimes (I think) 'why are you making so much noise over stirring...(the) sugar in your tea?'...(you don't) know (you're)...doing it so I can't tell (you) to stop because it is too much to expect of (you)..."

Clare's growing compassion for Anthony was nurtured by each new experience as she watched him struggle to do his best, constrained by deafness. While Clare's easy going attitude towards the noise made by their three children may well have been appropriate, Anthony expected her to be more vigilant as he would have been if he were hearing. Anthony complained:

> " ...you see if the children are making noise,..(Clare) will keep quiet,..but my friends when they come here, they tell me that my children are very noisy...If I could hear, my children would not make noise..."

Clare defended her assessment of the situation:

> "The children don't make unnecessary noise...(while) it looks like a lot of noise (eg., jumping off furniture), it's normal children's noises...the only visitors (who have) complained (are) childless,..they don't know what it's like..."

Thus parenting could become complicated when the father in his role of disciplinarian[51] could not hear. The discussion of parental 'role strain' resulting from deafness will be continued in Chapter IX.

Joe and Sarah also talked repeatedly about difficulties resulting from noise. Unlike Anthony, Joe could hear sound, but the sound he heard was often too loud.[52] He said:

> "I mean I get...(noise from children) all the time in the summer...I've got a place of business. There's a school about 150 yards down the road...and they've got their own playground, and when they come out, they're shrieking and I either have to turn my hearing aids down or shut the windows..."

While children's noises did not hurt Anthony in this way, Anthony's inability to trust his ears tended to spread to distrusting his wife's judgement more generally. Their associates sometimes appeared to exploit this situation. Clare admitted to feeling particularly upset at times. She recalled:

> "...If somebody says something,..and I'm trying to relate (to Anthony) what the person is saying,..(and) it's not quite exactly what he wants to hear,..(then) he blames me,..even though I'm trying to be helpful,..and that's what I sometimes find annoying...some people use me as a scapegoat."

Clare was understandably aggrieved when her efforts were misconstrued.[53] It was likely that part of Anthony must have on occasion felt scapegoated himself, wondering why he was the one to be singled out for deafness.

The fear that one partner would 'get the wrong end of the stick' was a difficulty often mentioned. This was not to say that this was not a common occurrence among hearing couples and Clare admitted that she also 'misheard' in this way. However, deafness appeared to exacerbate the situation.

So far it has been argued that couples, where one partner has sustained sudden deafness, have an intensely painful adjustment to make. The sudden loss of hearing has to be gradually accepted by both partners if the marriage is to proceed. Because of the complexities involved, it is a difficult and stressful undertaking and resembles a joint bereavement as the loss of a hearing identity is integrated into every day life experiences. The three couples in the study who were most affected by sudden deafness, Mike and Joy, Anthony and Clare, Robert and Mary, were able to overcome the potentially tragic aspect of the situation and psychosocially constructed 'deafness as a difference' respectively as a 'burden to be shared', 'a blessing, but sometimes problematic' and 'a challenging problem'.

Anthony and Clare's story was of particular interest because of the juxtaposition of the experience of sudden deafness with sudden migration and racism. All three experiences required a massive reordering to take place in their outer and inner worlds.[54] Thoughtful reflection about present experiences so that appropriate new identities could be forged, a process for which Anthony and Clare did not always have the energy, was continually necessary to avoid embarrassment. Clare acknowledged the difficulties by relating one example. She felt deep embarrassment that Anthony no longer spoke his native 'Ibo' when meeting members of his tribe in the UK. Although Clare did not say so explicitly, perhaps Anthony did not currently have the confidence that he could successfully lipread Ibo; and therefore spoke English, the language of the country which had 'adopted' him in his need for rehabilitation.

For the marriage to survive, hearing partners discovered that they became the front line, informal, full time rehabilitators as acceptance and integration began and progressed. They had to find the emotional strength to contain their partners as they struggled to synthesise the deaf and hearing parts of themselves. In this respect their experiences resembled the children of Deaf parents.[55] For example, Anthony wished to hang on to his sensitivity to noises from his 'hearing self', even though his new 'deaf self' could not actually hear them. In a similar way, Joy wished to hang on to all the friendships which she had made when she was hearing although her deaf self could not have intimate chats with them on the telephone. Joe, on the other hand, prided himself on coming from a musical family and delighted in his record collection although what he actually heard was bound to be affected by the inevitable distortion which still exists in hearing aid amplification. It was these threads of continuity which interwove to bring back a sense of normality and well being into the lives of the deafened people in this study.[56]

Some spouses refused to provide the demanding support needed at the time a profound hearing loss was acknowledged and their marriages fell apart. Their stories will be discussed at the end of this chapter.

The couples discussed so far had sustained severe, profound or total losses of hearing. We will now examine the three couples in the study where one partner gradually acquired their hearing loss which was of a mild/moderate degree.

WHEN THE DIAGNOSIS OF HEARING LOSS IS RELATIVELY RECENT IN TIME AND MILD IN DEGREE

ANNE AND ADAM

The literature suggests that people with mild/moderate hearing loss are likely to be better adjusted than individuals with more severe hearing loss.[57] Findings emerging from this study proved the situation to be more complex.

Anne, a social researcher, recalled how her husband Adam, an education manager, encouraged her to have her hearing tested as he had noticed she didn't always hear him. After seeing the audiologist who confirmed her mild/moderate loss, she reflected:

> "...but having been (diagnosed), I feel I have labelled myself..."

Having a 'label' made Anne feel odd and different in a way she disliked. She was also very unsure of the implications she said:

> "For example...our car insurance...says 'have you got any disability?' Because in a sense I have because it has been 'labelled' (but I also feel that) I don't want to draw attention to anything...it's not significant enough."

Adam added:

> "The most pronounced situation...(was) in the countryside in the summer...and the crickets were making a lot of noise and everybody could hear them (but)...Anne."

Anne had a different opinion:

> "...When I think about (people saying) there are crickets going,..(I think) other people are (just) imagining things...it was a holiday...it was outside of every day reality."

Anne was beginning to manage her hearing loss and she refused to become distressed about not hearing things which she saw as unimportant to the main thrust of her life and interests. However, music was a different matter. She recalled:

> "...just before Christmas, we went to a concert, and there I suddenly thought,.. 'Am I going to miss some of the higher notes?',..and that I would mind a lot,..but it was fine...(the music sounded the same as usual)."

Anne wished to test different situations to see how they were affected by a high frequency hearing loss.[58] Adam thought Anne was not fully comprehending the difficulties ahead. He recalled:

> "...(Recently)... I...(went) to dinner with some (African)...students, and their accents are very broad and very difficult for me to understand...I am certain that Anne would have been totally lost."

Anne disagreed with Adam's specific point, but thought he might be correct in principle as she had not been able to hear one of her students with a strong Welsh accent.

Once Anne had thoughtfully assessed the situation, she and Adam perceived the meaning of 'deafness as a difference' within their relationship as a 'problem to be watched'.

FRANK AND SIMONE

Frank, an academic administrator, also had a mild/moderate hearing loss. Unlike Anne, it had not been a surprise as mild deafness had been in the family. He recalled:

> " ... my grandmother...(and) mother (were also) deaf, but neither of my sisters or...other brother...(are), a lot is hereditary... it's...the chance factor...I've just got to accept ...that there are certain things I won't be able to hear."

Although Frank sounded stoical in his acceptance of his hearing problem, he appeared to need reassurance that he hadn't been singled out for some special punishment which his brother and sisters had escaped. Because he was both gifted and fortunate in both career and family life, his hearing loss appeared to represent 'an occasional source of sadness', something he didn't quite know how to address since it didn't fit in with his otherwise almost golden existence and well deserved achievements. Frank revealed how he managed these feelings:

> " ... there are times when I haven't heard something and I should have heard it and I've said (to myself) 'Oh, I feel sorry that I haven't heard it' and in that sense I feel a bit frustrated...on the other hand, what's the point of being frustrated all the time ?..it won't help me..."

Frank explained further how he had learned to cope:

> "...I suppose I go quiet. I mean my sister said to me, 'Were you all right on Saturday (night at my dinner party) because you were very quiet?' and I said, 'Well, I just couldn't compete'."

While Frank put his withdrawal down to his deafness, his wife Simone, disagreed for she said:

"...but I feel it was the same before you became deaf...Frank would go quiet before the loss of hearing because (that's his) personality."

Frank acknowledged her point saying:

" I don't like...situations in which a lot of people are trying to dominate,..I like a give and take situation in which people make a point...(then) other people might respond to that one."

Like Anne, Frank found some situations difficult and sought to maintain a sense of personal control by deciding whether or not a given conversation was important enough to ask for clarification. This capacity for discrimination had been acquired by both of them before becoming hearing impaired, but now it had an additional function. Anne and Frank's hearing partners, however, did not see their partner's withdrawal in social situations in the same positive light.

RACHEL AND RICHARD

Rachel and Richard are the last of the study couples to be discussed. Rachel was the only person in the study to have a conductive hearing loss called otosclerosis. This condition involves the deterioration of small bones in the middle ear. Otosclerosis is unlike sensorineural hearing loss in that it will respond to microsurgery. Rachel had one operation which was successful initially; but over time after the birth of her two sons, the condition re-emerged.

Rachel and Richard were the only couple in the study who openly acknowledged having a communication problem in their marriage for which they had sought professional help. Although Rachel's deafness may have exacerbated their marital troubles, neither partner saw it as doing so as hearing aid distortion does not occur in the same way with a conductive loss as happens in a sensorineural loss. Rachel and Richard had psychosocially constructed 'deafness as a difference' to mean 'a

nuisance'. She revealed this attitude when describing how she felt about the possibility of not having to wear hearing aids. She said:

> "I was very excited to think that without aids, I could go swimming, you know...could run around,..outside they whistle...yes, yes, they're a nuisance...(How I would) love to get rid of these awful things."

It appeared to be the wearing of the aids rather than her deafness as such which Rachel allowed to inhibit her from doing some of her favourite activities. This is puzzling as it is quite possible to swim without them, but only if one is comfortable with not hearing.

In comparing a mild loss with the experience of sudden deafness, there were fewer difficulties with which to come to terms, as communication and identity were not as severely affected. For example, there was no need for assistive aids except the hearing aid on occasion, and there was no pressure on the hearing spouse to carry a rehabilitator's role, although some 'awareness' was felt to be helpful. This was not to suggest that a mild/moderate hearing loss was insignificant as it had the tendency to spoil 'the perfect', especially for men who have been socialised to connect their feeling of manliness with being physically a 'complete man'.[59] A mild/ moderate hearing loss had to be thought about and managed by various coping strategies meaning that some understanding and appropriate sympathy was appreciated. However, the latter was rarely asked for or rarely received meaning that there is something especially isolating about having a mild/moderate hearing loss.

The next section will look at communication, the second process which enfolds epigenetically in relational systems.[60]

SECOND RELATIONAL PROCESS : COMMUNICATION

'Communication' is the second relational process under the Epigenetic Principle following attachment /care giving'.[61] It is a symbolic, transactional process or the process of creating shared meanings. Words or verbal behaviour are the most commonly used symbols, but a whole range of nonverbal behaviour is also included. To say that communication is transactional is to say that the participants have a mutual impact upon each other.

A transactional view of communication and a systems perspective complement each other because they both focus on relationships. In other words, relationships take precedence over individuals. As two people interact, each creates a context for the other and relates to the other within that context.[62]

COMMUNICATION AND GENDER

People in the study appeared to hold certain implicit assumptions about how women and men communicate as documented in the literature by sociologists,[63] psychologists, and linguists.[64] Sam, Joe, Adam and Frank liked to give the impression that 'women's talk' wasn't worth listening to, a defense often used by hearing impaired men.[65] However, gender is only one of a number of factors that seemed to influence communication in this study. Certain basic conditions were needed which will be discussed in the next section.

COMMUNICATION AND CONFLICT WITH REFERENCE TO TIME AND PLACE

The 'time' and 'place' of conversations were mentioned by a number of people in the study as significant in determining the effectiveness of communication. For example, Sam and Julia discovered that the best place for a conversation was in bed where they could relax, while Joe and Sarah felt the best time to talk was on Saturday mornings when they didn't have to rush off to work. Couples also had

their worst places for communication. Hearing Julia acknowledged that she had the greatest difficulty hearing Sam in pubs and in the street. Because Sam was unable to hear the volume of his own voice, he sometimes spoke exceptionally softly in these places. Clare has already introduced us to this phenomenon which occurred occasionally in her conversations with Anthony. Barbara and Ben and Joy and Mike talked about their communication difficulties when driving in a car after dark. The most difficult places for Joe and Frank were in the street or on public transport. Joe related:

> "...(when) we go on a bus (or a train), (Sarah and I will) sit together...quietly, travelling where we are going,.. and say nothing..."

Psychological and emotional factors also played a part in whether or not communication was effective such as the presence or absence of feelings of anger and hostility. Sometimes these negative feelings combined with hearing loss to cause conflict as Adam explained:

> "Sometimes...(Anne) will get irritated with me because she has asked me something (and)...I've replied,..but she hasn't heard (my response),..and she will then raise her voice in a slightly irritable way...(Although I have replied to her), she will shout at me..."

Anne defended herself:

> "I don't shout at you...it's to do with the feeling that (Adam) is not very communicative,..so if I feel I've said something that hasn't brought a response,..the meaning (to me)... is that <u>he</u> is not communicating."

This was an excellent example of how a relatively mild hearing loss could cause misunderstandings and exacerbate the difficulties in communication which were already present.

The next section will look at joint problem solving, the third relational process in Wynne's [66] schema.

THIRD RELATIONAL PROCESS: JOINT PROBLEM SOLVING

When the processes of attachment/care giving and communication have been relatively successful, they lead to the next relational process of joint problem solving. If communication has previously been dysfunctional, bogged down, or distorted by enmeshment or disengagement, this fact is most likely to emerge during the problem solving stage.

Joint problem solving was a difficult area to explore with the study couples because the partners appeared at times to have difficulty in identifying what was 'a joint problem'. This meant that one partner would identify a problem that concerned them, sometimes connected with hearing impairment and sometimes not, while the other partner would attempt to understand the reasons for their concern.

For example, deafened Joy and hearing Mary both found it problematic when their husbands engaged in great arguments with their grown up sons especially as visits from these sons were rare. The husbands, Mike and Robert, did not understand why their behaviour was problematic as it felt 'fine' to them. Two spouses, Frank and Rachel found problematic the way in which their partners expressed themselves. Frank felt his French wife expressed herself too dramatically resulting in his feeling berated at times, while Rachel felt her husband was under expressive resulting in her feeling taken for granted.

In a similar way, problems more directly connected with hearing impairment were not jointly experienced. For example, it was difficult for Ben to understand how frustrating it was for hearing impaired Barbara not to have 'subtitles' for the television; it was difficult for Clare to understand fully, how annoying the children's noise level was for hearing impaired Anthony; it was difficult for Kay to understand what a strain it was for hearing impaired Henry when he could not relate

to people properly during the noisy fellowship hour after church. Conversely, it was hard for hearing impaired Joe to understand how difficult it was for Sarah when she tried to help him while out shopping, or for hearing impaired Joy to understand how frustrating it was for Mike when he tried to balance his own needs with that of his wife's in social situations.

However, once a problem was identified and jointly accepted as such, the couples had no difficulty in working through the other steps. For example, Sarah and Joe identified the 'loss' of his two sons by his first marriage as a tragic problem. After a twenty year gap, Joe's sons were eventually contacted, welcomed into their home, and reunited with their father. Frank and Simone had agreed earlier in their marriage that the 'night terrors' of their twins were a problem, and Robert and Mary agreed that the emotional breakdown of their youngest adult son was a problem. In both families, the parents took steps to support their children through these critical times.

Thus the study couples had no difficulty in joint problem solving once the problem was jointly identified. This suggests that counselling work with couples where one partner is hearing impaired may need to focus on the identification and mutual acceptance of joint problems initially, and only later on the solving process itself.

The next section will look at mutuality, the fourth process which enfolds epigenetically in relational systems.[67]

FOURTH RELATIONAL PROCESS: MUTUALITY

The central aspect of 'mutuality' is that the partners have a shared commitment to one another to shape their relationship as the life cycle unfolds, as expected and unexpected events occur, and as new tasks, and aspirations emerge. Mutuality also incorporates a selective integration of the preceding processes of attachment/care giving, communication, and joint problem solving; and thus draws upon the

acquired relational experience and skill which has emerged from each of these prior stages.

The four aspects of mutuality which will be explored in the next section are distance management/cohesion, adaptability/change, leisure patterns, and the breakdown of intimacy. It needs to be recalled that distance management/cohesion and adaptability are two of the family dimensions identified by Olson and McCubbin[68] in formulating the circumflex model of marital and family systems. Here they are discussed under the heading of 'mutuality'.

MUTUALITY ONE : DISTANCE MANAGEMENT AND COHESION

Study couples managed their need for closeness and distance in various ways. Sarah, wife of severely hearing impaired Joe, feared too much time in his company would render her incapable of spontaneous conversation. She recalled:

> "But sometimes I just think I become very quiet, and of course when I meet other people, I have stopped talking, haven't I?"

Sarah's 'drying up syndrome' was not just a response to Joe's deafness, it was also a response to 'the differences' between people which are found in all intimate relationships. While Sarah knew the importance of social support networks to compensate for differences, some study couples were not interested in making such efforts, but preferred to lose themselves in reading, a good hobby or project, or simply time on one's own. Henry explained:

> "...When I'm studying, I take my hearing aids off my glasses and try to lose myself in what I'm doing,..so I'm escaping from the hearing world...(In this way, the outside of myself and) the inside (are) in tune with what (I'm) doing...(with no disturbing background noises)."

Henry recreated his sense of well being sometimes diminished in the 'hearing world' by concentration and total emersion in his studies.

Byng-Hall suggests that all partners, regardless of hearing ability, need time for escaping from their marriage.[69] Hearing Sarah, in making an issue of her need for distance management from Joe, had lost sight of the anthropological approach.[70] However, she regained it again when she focused on Joe's helpfulness:

> "...Joe listens and he's very good...the trouble is I have all the energy (to share my problems) at a quarter to eight in the morning when I need to be getting to work!"

Sarah pointed to the pressures of 'time' and 'place' as inhibiting factors in this kind of intimate dialogue. Sarah recounted a recent experience on holiday with Joe:

> "...We... wanted one week away without...(distractions)...I want(ed) to...talk to my husband, and for him to listen to me...we went and we got food, and we cooked it 'at home' so we could talk over our meals,..and we (had a wonderful time catching) up on things."

Although Joe might not have a talent for 'small talk', he was more than capable of being a good companion and participating in more advanced relational processes specifically intimacy and communication.[71]

MUTUALITY TWO: ADAPTABILITY AND CHANGE

Olson and McCubbin describe adaptability as being "the ability of a marital/family system to change its power structure, role relationships, and relationship rules in response to situation and developmental stress".[72]

Managing roles may become more complex when marriages must also cope with a disability. Role shifts or reversals sometimes take place that put extra strain on marriages.[73] Oliver[74] mentions difficulties with 'role overload' while House and Robbins mention 'role strain'.[75] (For a detailed discussion see Chapter IX).

The people in this study did not appear to have any special difficulties in managing household chores with respect to their disability. Specific difficulties were mentioned only once by the retired couple, Mary and Robert. Robert had troubles with decorating, heavy lifting, and cleaning, jobs he had done before he contracted Meniere's Disease. As a practical person, Mary did not resent Robert's withdrawal from these areas for she saw he was much happier absorbed in his writing and volunteer activities. Of the ten remaining couples, eight out of ten women, regardless of hearing ability, took the major responsibility for looking after the household. Husbands generally saw themselves as helpers or 'understudies' as described by Rapoport and Rapoport.[76] The two remaining men, Ben and Joe, took on more responsibility for family/household management as their wives considered most chores boring and preferred to focus their energies elsewhere. Joy was also in this group and it was hoped that a more balanced distribution of chores would occur after Mike retired. Four people in the study had hired help. Anne, Sarah, and Simone had weekly cleaning ladies and Rachel and Richard hired a monthly gardener.

Thus, unlike Parker's study,[77] this evidence suggests that traditional gender roles were barely affected by one partner having a hearing loss. Other contributory psychosocial factors were personal inclination, convenience, talents, and skills. A high degree of 'adaptability' was noted in that the partners relied on each other both to support and to counterbalance each others' movements.[78] For example, all the men in the study, whether hearing or hearing impaired, could look after themselves if their wives were away. Most of them had specific cooking skills and exercised them from time to time such as making breakfast, curries, casseroles, cooking with a wok, or making wine. There was a general feeling among the couples specifically Anthony and Clare, Ben and Barbara, Henry and Kay, Joe and

Sarah, that they made a successful team. This was particularly true in such tasks as entertaining, planning for a foreign holiday, and decorating.

MUTUALITY THREE: PATTERNS OF LEISURE

Changing patterns of leisure was a difficulty mentioned by couples where deafness struck after their marriage was established. Couples who had once enjoyed the theatre, the cinema, and dancing no longer received the same mutual enjoyment and stimulus which they once had done. Deafened Joy recalled:

> " With dancing, I think...to a certain extent it is pointless (because I can't hear the music)...There is some enjoyment... obviously..."

Despite the difficulties, Mike and Joy often choose holiday resorts where they could dance. Mike said:

> "I mean...(Joy) does get up on the floor at modern disco dancing ...even if she's never heard disco music...(before) !.."

Joy's inability to hear the music did not prevent her from responding to Mike's enthusiasms. Later Mike revealed that they had actually won a dance prize. He explained:

> "...Joy does follow...we don't make mistakes...I can still enjoy the music and the dancing at the same time...we won a dancing competition on holiday a couple of years ago."

Joy acknowledged her ability to follow:

> "...I sort of have a vague idea of music in my ...(head). I'm used to dancing with Mike and follow him easily, (and) I can follow other people."

Along with the following, there was a hint of skill. Joy also admitted that she was able to experience some enjoyment from the general atmosphere:

> "...it's not the same as being able to hear,..but to a certain extent you pick up the (atmosphere)... you more or less make yourself join in."

Because Joy knew that Mike would give up the dancing he loved if she did not go too, she tagged along in an effort to bring him happiness. Thus she was willing to compromise since she knew in other areas it was Mike who did the compromising.

It was noted that deafened Anthony, severely deaf Henry, and prelingually deaf Arthur all admitted that they had almost no leisure time with their wives. As all three were involved in serious courses of study, it was hoped that the situation would change after they completed their degrees.

Couples who met when one partner was already hearing impaired seemed to have fewer regrets with respect to leisure activities. From the beginning certain activities were established as ones which they enjoyed doing together while others were off limits. In the case of Barbara and Ben, a day out together meant attending a Lautrec exhibition or a visit to Hatchard's bookshop. Julia and Sam were both sporty and enjoyed a good tennis match or a walk in the country while Sarah and Joe enjoyed going on holidays to unknown parts.

The general pattern of couple leisure that emerged was a varied one. Some activities stopped, others were altered or restructured, and still others continued with little change. This did not seem significantly different from couples where both partners could hear as their leisure interests change and develop over the life cycle.[79] What was likely to be different was the criteria used when making decisions about leisure activities. That is, would a hearing loss be an obstacle to enjoyment?

Let us now consider what happens when couples lack the wisdom, love, or skill to manage 'deafness as a difference' or other difficulties within their marriage.

MUTUALITY FOUR: BREAKDOWN OF INTIMACY

One of the most significant social trends in post war Britain has been the steady escalation of marital breakdown.[80] People's behaviour in this study reflected the national trends. It emerged that one quarter of the study couples had experienced marital breakdown including one couple who divorced after the interviewing was complete. Although this figure roughly suggests that hearing couples have a higher chance of divorce than when one partner has a hearing loss, the situation is more complex. A brief analysis of the marriages that ended suggested a number of common factors.

A factor which united the four couples was that they were all in Stage IV in the Family Life Cycle, sometimes called the stage of adolescence. It is a time when marital satisfaction is likely to be the lowest and stress the highest.[81] The divorcing study couples had succeeded in getting beyond the average time of divorce for hearing couples of ten years; but had run in to trouble in the early part of their third marital decade: 20, 21, 22, and 24 years of marriage respectively.

The four divorcing couples in this study were placed in three groups. Two women formed the first group, Christine and Grace. Although they had both grown up knowing they were hearing impaired, as high spirited women, it had not held them back from personal, artistic, and academic achievements. Grace was an interior decorator and refurbisher while Christine was a gifted musician with a BA in music. However, Christine now 70, a retired marriage, family, and child counsellor, recalled her confused feelings before she married Jack:

> "...(Jack and I)talked to each other...(a little about my hearing loss),..I was still going through a 'denial' period...I remember thinking as (Jack and I) were driving off after Church,` Why are you going to marry me?..I`ll probably be stone-deaf before anything...no I can't (tell you) that'... I wanted to marry Jack, I wanted to have a family, I wanted to have a normal existence and for twenty-five years I did!"

Christine decided to a adopt a 'pretense' strategy.[82] Both she and Grace married high achieving verbal men and delighted in the role of 'helpmate'. Christine had three children and became the ideal doctor's wife. In hindsight, Christine wished she had been more honest with her boys. She recalled:

> "...If I had it to do over again, I would be much more open about (being hearing impaired). I...(didn't) want to burden my family with my troubles, and if I could work around it, I would..."

Christine's 'denial' of her deafness protected her family and herself from the reality of her growing isolation. Her attitude was similar to Barbara's and Ben's since they also wished to retain their children's innocence (see Chapter IX). While Christine immersed herself in family life, Grace and her husband, George, did not have children. Grace preferred to support their joint business by making good use of her contacts with 'dealers' and her flair in discovering tasteful bargains.

What the literature calls a 'critical mass'[83] formed when Christine and Grace's partnerships broke down and their 'pretence strategies' dissolved.[84] Grace confided her understanding of what had happened:

> "As far as husbands and wives are concerned, my private opinion is that (their happiness together)...depends on what sort of social position they have. After all, some people don't expect anything in the sense of a social life, even when they can hear. Their social life is very small. Whereas the higher on the social scale you go, the more you expect such as sophisticated dinner parties. My deafness put a 'lid' on this. My ex- husband, who is a great conversationalist,..said he could not see why he had to suffer too."

As Grace and George had built their marriage around a 'business and social partnership', the marriage ended when Grace could no longer keep up with her husband's social verbosity. George's so called 'commitment' had apparently

lacked the deeper roots of true emotional intimacy or an emotional 'couple fit' which could sustain an acceptance of 'loss' as part of the human condition.[85]

Christine and Jack's relationship was also built on the assumption of perfect hearing. When the 'denial' was broken and reality revealed, Jack's feelings of commitment also faltered. Christine recalled:

> "...he went off with another woman,...(but) he kept coming back. He really didn't want to break up the family, but he couldn't break up with this woman either, and he died (of hepatitis) a month after the divorce was filed..."

Although Jack died at the age of 50 in a state of turmoil, Christine was now free to put her relationship with her children and grandchildren on a more honest footing, and to develop her burgeoning career. With the passing of time, Christine forgave Jack as she was aware that only as an independent woman could she have found the courage to take control of her life.

The second category was composed of Joe and his first wife, Emma. Like Christine and Grace, his marriage was dissolved, but with a different outcome (See Chapter VII). Perhaps because he was more confident than they were, he did not hide his hearing loss and could inform people of its existence. However, he was never able to communicate his 'special needs' for attention fully to his wife Emma who focused most of her time and energy on their two young sons and her plans for their brilliant careers. Resentments grew and they parted. After the death of both his parents and a period of great loneliness, Joe married Sarah.

All three stories have one point in common. The deafness itself within the relationship did not cause the break up of the marriages despite the fact that the hearing impaired partners initially told their stories to the researcher in such a way as to make it appear that it had. This is because hearing loss makes an easy 'hook' on which to blame things. However, when the relationships were analysed, it

emerged that all three couples had substantial difficulties with managing 'differences' generally with the hearing loss representing one additional 'difference'. Underdeveloped communication skills were the main reason why these couples did not manage differences appropriately.

The third category comprised Adam and Anne who divorced during the writing of this study. The relationship was significantly different from the other three couples mentioned in that the hearing loss was never an issue in the marriage, although it is possible that it was an exacerbating factor (See Chapter XII for further examples of couples who experienced a breakdown of intimacy).

SUMMARY

The Epigenetic principle has been used for examining the ways in which hearing loss affects couples in their continuing relational processes. Attachment/care giving, communication, problem solving, and mutuality were examined. The couples concerned were significantly different from those in Parker's study[86] in their coping patterns, although there were also similarities especially during the time immediately following the onset of sudden deafness. In such circumstances, both studies revealed that it was 'the quality' of the marriage which determined whether or not it held together.

If the marriages were to move forward, the couples needed to agree on a way to perceive the deafness within their relationships. The three couples in this study where one partner was suddenly deafened described the deafness as a 'blessing, but sometimes problematic', 'a shared burden', and 'a challenging problem'. The three couples where one partner had acquired a mild/moderate loss described it as a 'problem to be watched', 'an occasional source of sadness', and 'a nuisance'.

In doing so, the couples continued the behaviour found in Chapter VII by focusing on 'differences' as part of an anthropological/ cultural model rather than on a medical model. If this did not produce a new equilibrium, the initial commitment

dissolved as occurred with four couples in this study. Their stories were told to illuminate some of the factors which cause marriage break down, and the specific place of hearing impairment. It emerged that deafness was an exacerbating factor to the breakdowns and one of many differences which the partners had difficulty managing.

In the context of a renegotiated contract, it is possible for 'care' to be interpreted as 'the roles' occasionally adopted by the hearing partner on behalf of the hearing impaired partner. For example, the roles which emerged were buffer, editor, interpreter specifically on the telephone, considered the most stressful, mediator, prompter, advocate, and editor.

There are, however, a number of difficulties in making this connection. Firstly, the help provided by the able bodied partner specifically the hearing spouse for the hearing impaired spouse rarely caused the distress found by Ungerson[87] and Parker[88]; although in certain specific situations, the findings suggested that stress, frustration, and resentment were caused. In acknowledging this, it needs to be remembered that stress, frustration, and resentment occur in every close relationship as these feelings are a part of human nature. Many would argue that the institution of marriage itself brings about negative feelings to an extreme degree as partially evidenced by the high divorce rate. Secondly, care was rarely provided on a daily basis, but only occasionally when needed for specific events. Thirdly, the hearing impaired member of every couple was employed in a paid or volunteer capacity, and able to function in the public sphere completely independently from their partner. Finally in focusing on this kind of 'care', it is not being suggested that the relationship was not reciprocal in the long term. On the contrary, a loving rapport on both sides seemed one of the most significant and striking features of most of the study couples. However, initially, it was not always evident how the eight people with the more severe/profound losses in the study returned the social access support that was so obviously and generously given.

The couple Anthony and Clare were chosen as a special illustration since besides sudden deafness, they also had to come to terms with sudden racism and migration. All three experiences involve a loss or change of identity in the present and the need to work towards a reintegration of what has been lost so that a reinvestment in the future may be made.

The loss of spontaneity within their couple relationship emerged as hearing partners' most frequent complaint. As often as this disappointment was acknowledged, it was also observed that there were other psychosocial factors which contributed to a more serious attitude within the marriage for example growing older, personality traits, migration/racial issues, and other problems and responsibilities. It was exceeding difficult to distinguish when a problem was the impact of hearing impairment, another factor, or a combination of factors of which hearing impairment was one.

From the couple, the focus will now shift to the family especially the impact hearing impairment may have on children, roles and the family life cycle.

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CHAPTER IX THE IMPACT OF HEARING IMPAIRMENT ON CHILDREN, THE FAMILY LIFE CYCLE AND ROLES

INTRODUCTION

Having considered the couple relationship as it forms and develops, it is now appropriate to consider the family unit when one parent is hearing and the other is hearing impaired. It is useful first to explore the theoretical foundations which are used in this chapter.

The family life cycle approach is generally associated with the developmental perspective over the life span.[1] It ranges from the formation to the dissolution of family units. Families are followed as they move through stages of development and the tasks associated with each. An examination is also made of the transitions between stages that punctuate the life cycle and represent major additions, losses or modifications of roles.

This approach is not to be confused with the family life course approach which many sociological researchers in the U.K. prefer because it allows for more "flexible biographical patterns within a continually changing social system".[2] In this specific study, the family life cycle approach was retained largely because the people's lives were relatively conventional in their structure, and therefore fitted the framework of the life cycle approach. However, it needs to be clarified that an 'ideal' is not being suggested or that there is a denial of the variations found in family life today.[3]

Lastly, the family life cycle has been found useful for examining the nature of family stress, a biological and psychological reaction which may be triggered by the onset of hearing impairment in a family member. Such stressors may or may not produce a 'family crisis'. Hill defines a 'stressor' as a situation for which a family has had no preparation so that members' ability to deal with it is problematic.[4] A family 'crisis', predictable or unpredictable, is described as occurring when the family can no longer make use of its resources (for example problem solving ability, common sense, communication patterns) in a way that "controls and contains the forces of change". [5]

While such a cross sectional approach has its limitations in that it does not allow for an assessment of changes from stage to stage, it does provide the opportunity to examine differences between families at various stages of the cycle. What still remains uncertain with this approach is which differences are due to variations in family life cycle stages, and which are due to the social and historical context within which each group of subjects or age cohort has lived.[6] Lastly, the stages used here are an abridged summary of the family life stages proposed by Hill and Rogers.[7]

In the following section, each family life stage is introduced and briefly described. Then findings related to each stage are analysed so that the usefulness of this approach emerges.

STAGE I: YOUNG COUPLE WITHOUT CHILDREN

The partners are adjusting to living as a committed pair in the first stage. Couples without children are likely to be both flexible and cohesive in their manner of relating to one another.[8] This implies stronger external than internal boundaries, with flexible interactional rules and roles.

The study produced two couples in this stage, Arthur and Gwen and Sam and Julia. While Arthur and Gwen were newly married and were experiencing a transition as they moved from Stage I to II in that their first child, a son, was born during the interviewing period, Sam and Julia had cohabited without children for ten years. They appeared to approach their relationship in the spirit of gratitude, a reflection perhaps of the fact that both of them had experienced considerable 'loss'. Children were being considered, but a decision had not yet been made.

STAGE II: FAMILIES WITH PRESCHOOL CHILDREN (0-5)

At this stage the family reorganises around the needs of the infant(s) and becomes a permanent system for the first time. This means that symbolically and in reality this transition is the key one in the family life cycle.[9] Even with dual career couples, there is

a return to more traditional sex roles usually resulting in a lowering of self esteem for women[10] and ambivalence for men.

Severely hearing impaired Joe was the one person in the study to admit to his feelings of jealousy towards his two sons. Nevertheless, it was the birth of his eldest son that helped him towards a more realistic assessment of his hearing loss in that it prompted him to purchase his first hearing aid because "children have soft voices". Such remarks underline the complex and powerful nature of parental feelings, specifically fathers' towards the birth of their children.[11]

After the birth of his baby son, profoundly deaf Arthur, admitted that he felt mildly excluded. His hearing wife, Gwen, had not only an infant to care for, but also a recently widowed mother.

Severely deaf Henry recalled feeling immensely proud after the birth of his son. Simultaneously, he felt somewhat envious of his wife because of the attention she received from concerned people in the community. He remembered that everyone always asked how Kay, the mother, was doing, apparently unaware how enormously involved he was as a father. Thus while Henry felt included in the family bonding taking place, he appeared to feel excluded from public recognition of the emotional and physical cost of that bonding.[12]

Henry was also concerned about whether or not his children would inherit his deafness. Although logically he understood that his own deafness was the result of his mother having had rubella, he was relieved when their son, Clive, was tested and found to have normal hearing at the age of eight months. This had not been a concern of his hearing wife, Kay, who had long before noticed that their son was responsive to sound especially to music, and that had been enough for her.

Henry was also concerned about whether he could lipread Clive when he began to talk. It quickly became apparent that Clive's speech like all children's, came gradually and Henry could easily keep up with it. Henry also discovered that reading a chosen story book together at the end of the day was a good way of nurturing their relationship and

his lipreading ability as well. Playing together with Hornby trains was another favoured activity for similar reasons.

Lastly, while Henry was working out the best way to communicate with Clive, Clive discovered that his father was hearing impaired and sought to adjust his own behaviour accordingly. Between the ages of two and a half and three and a half, Clive realised that having a 'deaf' father meant that he, Clive, had to go directly to his father if he wanted to tell him that tea was ready, and that he would not be heard if he yelled from the bottom of the stairs. However, understanding his father's need to lipread was a slightly more demanding exercise. For example, Clive, would sometimes start to talk to his father when his back was turned. When Kay noticed this, she would say to Clive:

> "Daddy is not hearing you because he's not looking at you."

This helped Clive's understanding to develop on how best to communicate with his father. Kay and Henry also recalled how Clive would sometimes stop in the middle of a conversation at the dinner table, and demand:

> "Mummy, look at me, I'm talking to you." or "Daddy, look at me, I'm talking to you."

Thus he had generalised the 'looking' behaviour to all conversations between adults and children. As he grew a little older, he was able to discriminate that it was his father and not his mother who needed to look in order to hear. However, he would still ask to be looked at by his mother if she wasn't responding to his conversation appropriately because of her other preoccupations.

The literature suggests that young children do need to experiment with the concept of deafness in relation to themselves. Although Leah Cohen did not have a deaf parent, she spent her early childhood living in the midst of Deaf people at the Lexington School for the Deaf in New York City.[13] She recalled putting pebbles in her ears to simulate hearing aids at the age of four. Not surprisingly, Clive also experimented by

claiming to be deaf when he didn't wish to respond to what his mother was saying such as 'Come and wash your hands for dinner'. Kay, concerned that Clive now thought deafness was something one could control, tried a little 'awareness' experiment with him. At one point, she stuck her fingers in both his ears explaining his frustration in not being able to hear was what it was like for Daddy most of the time. She added:

> "...and you (Clive) must't say you are deaf, because we know that you are not deaf."

This was rather a severe test for so small a child whose thinking is often primitive and magical.[14] On the other hand, Clive's responses were promising, and it was thought likely that he could cope with the lessons he was receiving since they were given simply and within a warm family atmosphere.

The above account reflects a child at this stage struggling with the meaning of deafness, a trait of his father's that required him to make certain adjustments before effective communication could take place. As he struggled with the concept of physical deafness in his father, he invariably stumbled on defensive psychological deafness in his mother and himself, namely not hearing when one was preoccupied or didn't wish to respond to what was being asked or demanded.

In comparing Henry and Kay's approach with the two couples who had latency aged children, the former were the most conscientious in their perceived responsibility to teach 'deaf awareness'. Perhaps partly because the children in the two other families were slightly older, their parents had difficulty in recalling these earlier stages. One couple, Barbara and Ben, seemed almost proud that they had taught nothing directly to their children about Barbara's severe deafness. The fact that Louise and Edward facilitated their mother's lipreading by facing her when they spoke, was seen as having occurred naturally without prompting from adults. They believed that further disability awareness would occur when the children were ready. Consequently, Barbara was prepared to put up with demanding behaviour in the desire not to spoil Louise and Edward's childhoods as naive hearing children.

For example, while Clive was learning at age three that he needed to fetch his father rather than call him from the foot of the stairs, Louise and Edward at seven and nine years of age were still calling for their mother when they were on one level of the house and she was on the other, and getting frustrated when she did not appear. Thus, Barbara's deafness was perceived by her family as a 'frustration'. Barbara and Ben's attitude appeared to reflect the following statement found in the disability literature:

> " We have to let our sons and daughters be children and do the things they want. They have their own little minds and their own priorities. We can't let them become robots for our sake." [15]

However, child development literature suggests that all children need some demands made of them.[16] Most small children are instinctively highly motivated to communicate with their parents verbally and nonverbally.[17] More often than not, children are happy to place themselves in front of their hearing impaired parent in order to facilitate communication, as they are rewarded by the interaction feeling warmer and more complete. When older, some children will feel pleasure from the helpfulness of their actions.

Barbara and Ben encouraged Edward and Louise to perceive their mother's hearing loss as a 'frustration', to be experienced alongside other frustrations of childhood. This raises the question as to whether they were depriving their children of the perspective of seeing their mother as <u>both</u> normal and deaf. Perhaps Barbara and Ben were overprotecting their children and themselves from this enriched perspective because they really didn't know how to manage to communicate it positively. The literature suggests that the reality of a disability can be presented to children without undue stress as long as it is accompanied with suitable reassurance. If managed sensitively, it may in fact lead to a new closeness between parents and children and a reduction of the frustration. Counselling can facilitate this process.[18]

STAGE III: FAMILIES WITH SCHOOL CHILDREN (AGED 6-12)

The family is re-organised once again to fit into the expanding world of school children. The family system now overlaps on a regular basis with other systems such as educational, religious and community. Although parents may feel less important once their children start at school and get involved in community activities, child development theory suggests that only a shift of need has taken place. This was illustrated vividly by four latency aged children in the study, Lisa, Louise, Tony and James, who gave explicit messages that they wanted a closer relationship with their parents than they had.

One example was Tony, Anthony's eldest son aged eight. During a private interview with the deafened interviewer, Tony asked the following question:

> "Is it hard to be deaf?"

It was felt that this was a question Tony would have liked to ask his father directly, but was slightly fearful of his response. Tony also recalled:

> "...and (the) most difficult thing is when (my dad is) in the bedroom and he locks the door. When you want to tell him something, he can't hear."

Barbara's daughter, Louise, aged nine, echoed Tony's complaint. These two eldest children could handle the physical deafness of their parents on its own with equanimity, but it became difficult when compounded with a closed door. Although all parents need their privacy from time to time, children often require considerable maturity not to perceive withdrawal behind a closed door, if only temporary, as exclusion.
Tony recalled some good experiences:

> "...sometimes...(my Dad) gets what we're saying...the first time he gets close to the word, the second time he gets the word...or if the second time he doesn't, we help him".

Tony knew he could help his father, but did not appear to feel overly responsible. There seemed to be an understanding amongst the whole family that doing things for Anthony would not reverse the parenting role, as helping was seen in the larger context of satisfying a temporary need within the parent/child relationship. Tony also knew that his hearing mother was there and all the children believed in her capacity to "make him listen."

It is significant that Tony used the word 'listen' rather than 'hear' suggesting that he and his siblings were more concerned with their father's capacity for concentration and understanding rather than the biological capacity 'to hear'.

Children of the opposite sex from the hearing impaired parent may receive more reassurance in some circumstances. Clare and Anthony's only daughter, Betty, aged six, was allowed to climb up onto her father's lap and test out her power/caring fantasies that she could make him hear by yelling in his ear! In discovering that her efforts were useless, it might at first be disappointing; but she could also be reassured that she was in no way responsible for her father's condition and therefore need feel no guilt about it.[19]

Conversely, on the other hand, James aged eight at the time his mother was deafened (see Chapter VI), did not apparently receive this reassurance. This was reflected in James' way of coping which was to simulate a kind of deafness in himself by spending much of his free time in his bedroom when he had formerly been a sociable little boy. Because of their socialisation, it is likely that daughters more than sons will be aware of parental vulnerabilities as well as feeling less threatened by them, and therefore, more able to ask for direct reassurance about them.

Children of this age had other ways of coping with their anxiety. For example, Tony worked at getting his facts straight. He recalled:

> "My Dad didn't used to be deaf. When I was about two or three, he was all right...so that's when he became deaf...because he had this drug in hospital... he nearly died."

Being knowledgeable about when his father was deafened in relation to himself appeared reassuring; like his sister, he need not feel responsible. His parents could also recall Tony asking:

> "Was it an operation you had on your abdomen?"

Being knowledgeable about how and where his father was deafened was also an important matter for him. Lastly, being knowledgeable about his father's exact limitations seemed to help. He recalled matter-of-factly:

> "...and when he's speaking on the phone,.. he can't hear anyone talk. He has to just talk."

All these older children who were able to think in a rational conceptual way identified with their parents and their troubles. Tony, with his parents' support, had done exceptionally well in clarifying what had occurred. The only area he expressed uncertainty about was his father's feelings.

Generally, it could be said that none of the children at this age in the study were subject to inappropriate pressure from an overdependent hearing impaired parent. The literature suggests that on occasion this has been known to be a problem and children have been allowed to become too powerful as their parents' 'ears' or as interpreters[20]. However this is more likely the case when both parents are deaf. Arthur who had found himself in this situation recalled:

> "...when I was growing up (I did feel a responsibility to help my parents),..<u>now</u> I...(interpret) out of a sense of duty... everyday things like making appointments with bank managers... impatient people...like the Inland Revenue, I have to supervise the whole thing."

Generally Arthur did not feel overburdened by these duties and enjoyed them to a certain extent.

As there were no signs that children were given responsibility prematurely in this study, there were also no signs that children experienced difficulties in language acquisition. In other words, none of the children had delayed speech development nor had they picked up any signs of Deaf speech. The fact that this rarely happens has now been well documented.[21]

The children in the study were not, however, as anxiety free about parental deafness as their parents thought. In fact evidence emerged that parents' endeavours to protect their children and themselves by not discussing the hardships of deafness probably led to lost opportunities for interaction and warmer relationships in some families. It was also noticed that the children's behaviour and spirits were in no way oppressed by the formidable quality of parental deafness. This was observed in the way the children were prepared to test limits and make bids for attention in much the same way as children of hearing parents. It is likely that the presence of the parent whose hearing was dependable gave sufficient security to compensate for the extra anxiety the children sometimes felt.[22]

There is evidence that children at this age are just beginning to become aware of attitudes of people outside the family, to the disability of deafness generally and their parent's disability specifically . For example, Barbara recalled how her nine year old daughter, Louise, reported that another child had asked her why her mother had a 'funny voice'. This had resulted in an uncharacteristically protective response from Louise:

> "She's the best mother there is."

Preston recalls the views of Linda, another child of Deaf parents, as she looked back on a childhood which contained similar tensions. Linda recalled:

> "Growing up, I was teased a lot. Kids made fun of how Mom talked. They made fun of her expressions. And you know, it was hard to separate it out. But in my house, that's my Mom. That's her way. That's what we do...." [23]

Both Louise and Linda were struggling with how to sort out family and societal versions of normality.

STAGE IV: FAMILIES WITH ADOLESCENTS

At this stage the family reorganises to fit into the adolescent's need for a rooted family to which it may return from individuating experiences.[24] Marital satisfaction is likely to be at its lowest and stress at its highest. This is because, as families move from the earlier stages of development into adolescence, family cohesiveness decreases resulting in the family's increasing interaction with its environment.

Researchers suggest that children, teenagers, and daughters of all ages, are particularly impatient with deafened people and sometimes deliberately provoke their hearing impaired parents.[25] The child development literature suggests that daughters during adolescence may vacillate between a caring and noncaring role depending upon whether they are feeling closer to a caring mother or a career orientated father.[26] Other researchers find the opposite pattern in that teenagers are found to be consistently tolerant, cooperative, and supportive.[27]

However, Joe's teenage sons had never adjusted to their father's severe hearing difficulties and even denied its existence. Anne's son, Rupert, aged 15, appeared to be more aware of his mother's milder loss. Anne recalled:

> " I think Rupert does know (I'm a bit deaf as he) does occasionally get cross. He yelled...recently when I asked for repetition, 'You are deaf, you are'...perhaps he was being factual as well as insulting...it's his way of relating to us."

Anne didn't feel that Rupert was particularly supportive, but then she hadn't raised him to be. His behaviour contrasted sharply with Shirley Ackehurt's three teenage daughters.[28] They were so strongly identified with their deafened mother that each had to have their hearing tested as they reached puberty in an effort to reassure themselves that they could, in fact, hear normally.

There is no attempt in the literature to interpret why teenagers vary so much other than it being a natural reflection of the range of maturity. Certainly, the model provided by the hearing spouse was an important factor. For example if the hearing partner is calm and patient as in the case of Rachel and Shirley's husbands, their children are likely to follow suit to a certain extent. Conversely, if the hearing parent is impatient as was the case with Sam's wife, the children are likely to emulate this behaviour.

STAGE V: YOUNG ADULT LAUNCHING

At this stage, the family reorganises into an egalitarian unit and releases its members. Depending upon the state of the marriage, this may be a time of liberation for the couple, a time of mourning and sadness, or a combination of both. It may also be experienced differently with the wife feeling one way, and the husband feeling another.[29] Paradoxically fathers, perhaps realising they have missed most of the intimacy of their children's development, may begin to seek a closeness from their wives which they have missed; while women after years of focussing on caring for others, begin to feel energised about developing their own lives, careers, and friendships outside the family.[30]

American Rachel and English Richard from this study had two sons: William (19) and John (17). Leaving home meant going to the USA either to attend university or to travel. Although in some ways this was a very painful time particularly for Rachel, it was softened by the fact that both boys had chosen to explore her homeland. William and John were proud of being half American and were both interested in working in the film industry in the USA.

Although William and John might inherit their mother's otosclerosis, a conductive hearing loss requiring her to wear two aids, neither son was concerned about this. They knew that their mother had been far more unhappy about other aspects of her life, for example, that she was living in England where she felt she was not fully appreciated, and that she and their father, Richard, were not more compatible. In the past Rachel and Richard, a self employed accountant, had in fact had a years' marital

counselling; but Rachel felt nothing really changed. On numerous occasions in her frustration, she had considered leaving the marriage and returning to the USA. She had not done this as she knew she had become a relative success as a 'Londoner'.

It was understandable that as her sons left home, Rachel's feelings of loss were reawakened. She used the research interviews to express some of her frustration and to rethink her priorities. Although Rachel and Richard denied any connection between her hearing loss and their marital tensions, it was likely that there were subtle connections. Research suggests that even a very mild hearing loss can prevent a person from displaying the capacity for vivacity, an excellent memory, an alert and powerful integrative intelligence and even humour.[31] Because Rachel had such a powerful, dramatic personality and was a dedicated university lecturer in the process of completing her doctorate, her hearing loss had not masked any of these qualities in which in fact she excelled.

However, Rachel's personality also resulted in a certain imbalance with her husband and sons. Indeed, they resented the demands her 'highly strung' personality put on their own quieter male natures leaving them unsympathetic to her loneliness and isolation. Since members of families often seek reparation for past negative feelings, it is possible that in becoming interested in the film industry in the USA, Rachel's sons were attempting to transform their attitudes.

STAGE VI: THE MIDDLE YEARS: A FOUR GENERATION FAMILY

The concept of 'middle age' suggests that on the one hand there is an emphasis on rebirth and fulfilling one's potential; and on the other, there is depression and sadness resulting from unattained goals and the condition known as the menopause.

During this stage, reorganisation around the marital partner continues as the children are now away most of the time.[32] Research suggests that there is the possibility of marital satisfaction increasing and continuing into the next stage.[33]

Frank and Simone, the study couple representative of this stage, were very much in the tradition of the pivotal middle generation. They were effective planners and decision makers and were particularly sensitive to the needs of the generation above and below them.[34] They had twins, a boy and a girl, who were now both married with careers and children of their own. Frank and Simone owned a second home in Provence, and it was here that four generations of the family gathered at Easter and Christmas.

Frank eventually acknowledged his mild sensorineural hearing loss in his mid fifties when he was given two NHS hearing aids. He then established a discriminating routine for wearing them as he did not wish for more amplification than absolutely necessary.

While Frank's hearing loss caused him some frustration as it diminished his control and choice in certain circumstances, Simone was not particularly sensitive to this as she tended to compare his condition to her father's more severe loss.

Because of this comparison, Simone's public account[35] was that Frank's hearing loss was simply not a problem. Although she was aware that the television was now usually on a bit louder, in certain respects, this was just another difference in preference between them. There was the implicit suggestion that learning to cope over time with their basic cultural differences, in being English and French, had prepared them to some extent for all other differences such as hearing loss. On a more intimate and private level, Frank admitted to being 'told off' occasionally by Simone for adopting a 'pretence' coping style.[36] Simone reflected on how she saw their relationship at this stage:

> "I think we've reached an understanding where we're more willing to talk (things over), and I'm more willing to put my point of view more calmly...we've grown up."

After a long struggle, they had found a more peaceful civilised way of being that seemed to suit them both for Simone added:

> " We (also) have long silences, but they're meaningful."

Frank and Simone knew that some silences were not always meaningful especially with Simone's father. When they were at their holiday home in Provence, they did their best to improve the quality of his life. They also welcomed the youngest members of their family including their three grandsons aged 8, 5, and 3, bringing the total to ten guests. Simone recalled their grandchildren interacting with their great grandfather:

> "It was very sweet to watch...the little ones and my father ...although they didn't speak the same language...they got on with gestures, and they cuddled...They watched tv together..."

Dialogue between the very young and the very old appeared to be a less important factor in establishing family rapport than a simple presence and an appreciation of children. Frank remembered how he responded to his father-in-law.

> "...we were cleaning up the house and (I) had a glass of beer...and sat down next to (my father-in-law) and talked to him and that was alright. He asked questions and I answered them slowly and...(we had a chat)..."

Frank also made an effort with his grandsons, He recalled:

> " ...A lot of...times...(my grandsons) are simply recounting what they've done and...seen,...sometimes...I find it difficult to follow exactly what it is (they are on about)...I usually keep it going by saying, 'Mm..yes..sure..mm!' But (they've) got used to me and I say to (them), 'Come a little bit closer if there is something important you want to tell me..."

Since Frank persisted patiently, he was rewarded in acquiring a certain level of closeness with his grandsons.

The example of Frank and Simone suggests that regardless of hearing impairment, the 'empty nest' period can be a time of great range and involvement, when the marital

partners are more secure and at peace with each other, with their careers and the wider community, and with their parents, grown up children, and grandchildren.

Obviously all families are not as fortunate as this. Illnesses can occur and mental health deteriorate. In this small study alone, one couple divorced, and one hearing impaired husband had a massive heart attack and died.

It emerged that cross generational misunderstandings about hearing impairment were more likely to occur in step families. An example of this occurred when Sarah's two grandsons came to visit some years after she married her second husband, Joe. She recalled the following incident:

> "So we are in the kitchen...(My grandsons) came in with their toys on the floor...just to be near us...but you see they want to talk to each other, and I'm wanting to tell Joe about something that happened to me at work last week...and the boys keep talking, and Joe was getting cross..."

Eventually with so much tension about, Joe's patience snapped and he became angry at one of his step grandsons. It was at some cost to Sarah for she continued:

> "...and I was so hurt...for Joe because he hadn't understood what...(the little boy had) said, and just as hurt for the little boys. They were trying their best to understand and I'd had...to stand them together and say, "You know, Grandad can not hear a thing without his hearing aid...but his hearing aid makes everything too loud, but...a little five year old and seven year old can't understand that, and it's pretty awful."

Sarah was a proficient mediator, although not without considerable 'role strain'. Joe was not unsympathetic to his grandsons' viewpoints for he added:

> "I walked out of the room...I didn't want to make the situation worse than it was...I was quite upset too...not for myself, but for the children because it's frustrating."

Peace was eventually restored. Sarah recalled:

> "In the afternoon, Joe was sitting over there and my other grandson said to him, 'Can I come and have a cuddle, Grandad?' ...and he just went and sat on his lap...and I said, 'Grandad loves you. He'll always be here to look after you...you both know that'...but it was an uncomfortable half an hour..."

While step parenting may be delicate when one partner has a hearing loss, as we have seen, natural grandparents also have their difficulties. However, it is possible that the more recent bonding of step parents will make competition and insecurity a stronger feature of intimate relationships.[37] Also in comparing Frank and Joe's response to their grandchildren, it needs to be remembered that Joe's hearing loss was considerably more severe than Frank's and he had been deaf for a longer time.

STAGE VII: RETIREMENT AND AGING (MALE OVER 65)

The emergence of retirement is one of the most significant social trends of the past fifty years.[38] It is the stage in the life cycle when hearing loss becomes a common condition usually in the form of presbycusis. This was the diagnosis of four people in the study: Robert, Theo, Max and Frank.

Robert (70) had also contracted Meniere's Disease just prior to his retirement. Besides losing his hearing within a period of six months, he also experienced attacks of vertigo, blinding headaches, and tinnitus. Robert confronted his illness head on by taking sign language and lip reading courses. Eventually, he discovered the radio microphone as an assisting device and used it on a regular basis with family, friends, and in the community groups he attended and chaired.

Although grown up children are not as vulnerable as younger ones, Robert's adult children, nevertheless, were deeply affected by his condition. By interviewing three of his four children, along with his wife Mary, a rounded picture of the most pronounced attitude changes emerged.

Robert's eldest son, David, an educational psychologist, put the family's initial reaction in context by explaining how his father had formerly been a passive, but responsible parent. It was their mother, Mary, who was the important one. Occasionally, Robert would emerge from behind his books and ask for repetition of bits of family conversation. David recalled:

> " I think (Dad) wanted to be in control of what he had access to...so in a sense everything you said had to be available to him, but the choice was his..."

David's observations support the literature and the generally understood role of the husband/father as controller of information.[39] However, there was a second level of meta-communication that was taking place within this family.[40] David added:

> "...the deafness took away his choice in the matter...we would make some very silly comment...we would have to repeat it three times...we could never get away with saying the standard thing 'it doesn't matter' because it always did..."

Robert, like Max, (see Chapter X) knew implicitly that so called 'trivial' conversations were important in that they reinforced a feeling of 'belonging' in some families. However, Robert did not know how to articulate his needs appropriately. David recalled:

> "...There were occasions when...(Dad) was very hurt (and there was a lot of anger around),..there certainly was an element of 'if you cared for me, you'd (include me in your discussions)'... maybe I reacted like it was a manipulation ...(which) may have been...unjust to him."

At this point Robert's hearing loss became a 'stressor' as the family did not have the resources to effectively handle it.[41] David continued:

> " We are an articulate family up to a point, but there...(are) quite a lot of things we would not talk about, and I think the question of people's feelings comes below the line...I think it's a habit rather than an actual taboo..."

An unpredictable family crisis had occurred. This meant the family's intellectual culture which did not discuss feelings,[42] initially lacked the resources to manage Robert's deafness without precipitating further anger and stress.[43] Because Robert was unable to articulate directly how frustrated he felt, the development of his children's compassionate feelings for him was delayed.

Robert's hearing loss has been considered in terms of how it affected his family as a group. Changes also occurred individually with each child. For example, David acknowledged how his father's deafness caused them to become more supportive of each other and less competitive as they faced together Robert's genuine limitations. David recalled:

> "...people might say...Dad's more at ease with (his disability than he was),..I think you see that more in (our debates)...he and I are happier to agree to disagree than we were three or four years ago."

Thus for David, their debating passion had dissipated into some sort of acceptance of the situation. Robert's relationship with his younger son, Paul, also changed. He had always admired his father greatly, but felt it impossible to keep up with him intellectually. Eventually Paul found work in the post office as a telegraphist. Later he was transferred to Brussels and worked for the European Economic Commission operating a telex machine. Sadly, his emotional health deteriorated. Eventually he had a nervous breakdown not long after his father was diagnosed as having Meniere's Disease. As Robert was now retired, he went to live with Paul in Brussels for three years attempting to help him regain his mental health and competence. Unfortunately, Paul's health remained unstable, and eventually they both returned to England.
Initially, Paul recalled being upset by his father's deafness since it made Robert fall off the 'parental pedestal' he had made for him. It had taken ten years for Paul and Robert

to rebuild their relationship, this time based on mutual acceptance and a deeper understanding of their own and each others' humaness. Paul reflected:

> "...I think we get on better if we go to a restaurant and we are face to face...then (my Dad) can see my facial movements, lips, teeth, eyes, and I can see him and then realise, 'Oh that is my dad' you know."

Although Paul was still officially 'mentally ill' in that he was periodically readmitted to a psychiatric day hospital for treatment, he was, nevertheless, poignantly sensitive to the way his relationship with his father had become more reciprocal in certain situations.

Robert's role in his younger daughter's life had also been crucial. Molly, a mother and GP sensed early on how frustrated her father was professionally. Perhaps because Robert had not found job fulfilment on lower levels, he had encouraged all his children to reach for the top regardless of gender or disability. Molly was pleased to see how her father was able to practice what he preached by gaining back his old confidence with family and strangers. She recalled one incident the previous Christmas:

> " My husband had just written a Pantomime...for the family, and my father was one of the Ugly Sisters and...(Dad) had the rather unkind name of 'deaf-as-a-Post Purveyor', but he didn't mind...he had his words and one of the grandchildren would just prod him when it was time to speak,..he was wonderful."

Adjustments were also required for Robert's wife, Mary. David and Molly knew how Robert's disability often left Mary feeling quite isolated: Molly said:

> "I'm aware how lonely it has been for...(Mum). She loves to ...be in a conversation,..she doesn't like silence. If she can't think of anything to say, she'll sing...so I think (Dad's deafness) has been very hard for her and I am aware that she has been low over the past few years..."

Mary was likely to be mourning a certain loss of domestic sociability as Sarah in Chapter VIII described. Mary recalled:

> "...when I see other couples together...chatting.., you do realise you're missing out...(as Robert) always used to be joking and quoting poetry and singing...occasionally we get sparks of it now...I suppose it is the hearing problem a lot of it. Maybe I don't respond the right way...we change, don't we..?"

Mary and Robert's spirits were undoubtedly dampened by all the 'unpredictable crises' in the family which occurred in a relatively short period (1979-1985). However, such a 'pile up' of stressful events is not unusual in family life.[44] Nevertheless, the need for practical strategies to manage Robert's specific deafness remained. He explained:

> "...Our...children... will forget...They start talking together and I just cannot follow what they're saying...So there I am standing in a group...but not of the group...Maybe they don't want me to...(be there). If I could hear what they're say, I'd know whether I was part of the conversation or not...so there is difficulty, although...on the whole, they're pretty good."

Robert's relationships with his grandchildren varied. In some ways he found it easier to relate to his Canadian grandchildren since they played badminton, tennis and computer games with him. It was also probable that as products of North American culture, they were less fearful than their English counterparts of speaking up to adults.

Regardless of Robert and David's breakdown in health, Robert and Mary were helped to mobilise their natural resiliency by receiving excellent medical and psychological guidance. Their level of functioning and feelings of well being gradually improved, making it possible for them to continue with community commitments as well as family ones, although Robert often needed Mary's support in his endeavors.

The next section is concerned with a deeper analysis of the impact of hearing impairment on the execution of adult familial roles.

THE IMPACT OF HEARING IMPAIRMENT ON THE EXECUTION OF FAMILIAL ROLES

INTRODUCTION

Rehabilitators have been concerned with the impact of hearing impairment on children, but also as beneficiaries of the effective execution of familial roles.[45]

'Role strains' are the relatively durable problems, frustrations and conflicts which both genders may experience in executing their familial roles effectively.[46] While roles in connection with household chores have been discussed (see Chapter VIII), the focus in this section will be on what makes a 'good enough' hearing impaired wife and mother, and what makes a 'good enough' husband and father.[47]

BEING A 'GOOD ENOUGH' HEARING IMPAIRED MOTHER AND WIFE

Women's primary role is still seen by the literature to revolve around her biological capacity to become a 'good' mother. This has sometimes been referred to as the motherhood mandate,[48] and has been interpreted to mean that the mother in a family must spend the majority of her time and energy caring for her children if she is to fulfill herself as a woman.[49]

The four hearing impaired women in the study who were also active mothers did mention mild feelings of concern in certain aspects of their mothering ability. The most informative account came from severely hearing impaired Barbara who had two children aged seven and nine.

Barbara thought that perhaps her children might be affected by the fact that she was not a very patient person, namely that she had a 'short fuse'. She did not connect this directly with her deafness since she knew hearing mothers who behaved in a similar way, but more with her personality. Two specific concerns were the fact that she was not always immediately accessible, and she found it difficult to monitor the children's behaviour. She felt her accessibility was partly hampered because of her difficulty in

doing more than one thing at a time, for example, lipreading a new friend, an exercise which required her entire concentration, at the same time as giving attention to her children. She knew that this sometimes resulted in rude interruptions on the children's part due to the frustration of being ignored when they wished to converse immediately with her. Barbara felt that they were not really old enough to appreciate her very special need to work continually at her social life to avoid negative attitudes and isolation. Nor could they fully appreciate that when she did give them her attention, she gave everything.

Barbara also experienced some difficulty in disciplining her children appropriately for she was never quite sure when they were behaving inappropriately. Since her brother and sister had been substantially younger than herself, she had rarely experienced so called normal sibling repartee; nor, because of her deafness, had she had the opportunity to overhear other peoples' children. She reasoned that her present doubts were connected with this deficit in her experience. Even when she did feel confident as a disciplinarian, she sometimes found it difficult to monitor her voice to reflect her feelings accurately.

Lastly Barbara was aware that her difficulties in hearing meant that she herself at times was inadvertently the rude one. For example, when the family was spending the day on an outing in the car, she would sit in the front seat next to her husband at the wheel and sometimes began to speak to him, not realising that one of the children in the back seat was already in full flow.

The literature suggests that the role which is second in importance for women has been the marriage mandate. Until the last half of the 20th century, marriage often facilitated womens' entrance into the world of adults.[50] In marriage, women are encouraged to adopt what many have seen to be another primary responsibility, that of becoming a homemaker.[51]

Joy was the woman in the study who experienced the most strain in her role as a wife after she was deafened from meningitis sixteen years into her marriage. The marriage had initially been built around full 'equity',[52] in that all aspects of life were mutually shared. Once deafened, Joy found that she had too much time for her disliked

homemaking tasks since her new job as a school dinner lady was not as demanding as her previous work of overseeing a business with her husband. Simultaneously, she discovered she was less capable at formerly enjoyed social and leisure activities, namely talking on the telephone and being her husband's dancing partner. Although she coped extremely well with these deprivations, it was apparent that her sense of worth had lowered because she no longer felt herself to be on equal terms with her husband. This was poignantly expressed when she referred to herself as 'tagging along' in his life.

We will now see how the men in the study also experienced 'role strain'.

THE MANAGEMENT OF ROLE STRAIN FOR THE HEARING IMPAIRED FATHER AND HUSBAND

The literature suggests that men's roles are more diffuse than those of women and do not focus on the elements of parenting and marriage to the same extent. Research also suggests that men are socialised to adopt norms which are competitive and controlling with little room for understanding vulnerability.[53]

In this study there were seven hearing impaired men involved in committed relationships. Although six out of this group were fathers, only two had young children at home. Severely deaf Henry had a one year old daughter and a three year old son. Deafened Anthony had sons who were five and eight, and a seven year old daughter. Although the traditional men's roles do not call for involved fathering, these two men both sought involvement and closeness with their children which resulted in a varied response from their wives. One was enthusiastic while the other was much more ambivalent, treating her husband as if he was more of a nuisance at times than a help.[54] This greater involvement was likely the result of the fact that both men were mature students and spent more time at home with their studies than they would have done in paid employment.

Like Barbara, Henry and Anthony were both concerned that their hearing losses should not prevent them properly disciplining their children. For Henry, unlike Anthony, noise

control was not a problem. He was more concerned with his lack of certainty about what were appropriate limits for his one year old daughter.

Although this group of men were able to talk about how they experienced role strain as fathers, they were more reticent in speaking about how they fell short as husbands. The hearing wives spoke more openly saying that they missed their husbands' ability to be intimate when they had their hearing aids out at night, to be protective when in public, and to be more fun in social situations.

SUMMARY

Because the literature in the field of acquired hearing loss has oversimplified the discussion of the impact of acquired hearing impairment on children's lives, this chapter has focused primarily on all the study children's attitudes and feelings, and an effort has been made to analyse their responses to acquired hearing loss in one of their parents.

There were a number of factors which persisted throughout the whole life cycle. It appeared to be the case that deafness could have a negative impact on children in that it made them worry or feel resentful, but that these feelings could be modified by sensitive management of the disability and the children.

Although the children in the study were encouraged to facilitate lipreading by facing their hearing impaired parent when speaking suggesting some control, none of them seemed to feel the sort of awesome responsibility which can occur when both parents are deaf. There appeared to be a direct connection between their relatively relaxed attitude and the fact that the hearing parent was present and had a stable relationship with their hearing impaired parent. There was a tremendous range found in 'when' parents told 'what' to their children about deafness. Some parents started as early as three or four years of age with articulated explanations in response to their child(ren)'s growing awareness that something was slightly different about Mummy or Daddy, while others preferred a more laid back 'wait and see' approach. The first approach was supported by parents who wished to instill a strong sense of responsibility in their

children, while the second approach was initiated by parents who wished to preserve their children's innocence as long as possible. It is argued that the latter approach may protect children and their parents from the enriched perspective of understanding the hearing impaired parent as being both deaf and normal, different and the same.

There was no support for suggestions in the literature that children, specifically adolescents, may reject their hearing impaired parent and that grandchildren inevitably upset their hearing impaired grandparents. On the contrary, it was found that grandchildren, like children, will make appropriate adjustments if helped to do so. When grandparents experienced difficulty, they were usually those who had not had positive experiences with children in the past or did not particularly like children.

The evidence reinforces the idea that rehabilitators of hearing impaired people need to have a sound grasp of the family life cycle approach and to have some understanding of the 'role strains' which are experienced.

From an examination of family life, the focus of the discussion now moves to the development of kin and friendship networks.

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CHAPTER X THE IMPACT OF HEARING IMPAIRMENT ON THE SOCIAL NETWORK: KINSHIP

INTRODUCTION

While earlier discussion has centered upon the impact of hearing impairment on the couple and the family, the next two chapters will focus on the impact of hearing impairment on the social world of the couple, their social network. This chapter will specifically look at the couple's kinship patterns.

The importance of social networks cannot be overestimated. Researchers have even suggested that the natural immune system is to the body as the kin-friendship network is to the individual.[1]

Although research has begun into the social networks of so called deprived and disabled groups, there is little in the literature pertaining to the networks of people with acquired hearing loss. This is not a reflection of the perceived lack of importance of social networks for hearing impaired people. On the contrary, this study supports the literature when it suggests that the degree of psychological distress experienced by people with a hearing loss is more closely correlated to the level of social support given from social networks than to the actual degree of impairment.[2]

This study suggests that hearing impaired people do not receive the support of sufficient quality from their kin that is conventionally assumed, a problem which is partly culturally based. By culture is meant highly specific systems that both explain things and constrain how things can be known.[3]

These difficulties are considered in more detail using the three levels of social network formation suggested by Unger and Powell[4] in order to provide a context within which the experiences of the people interviewed in the present study may be understood.

SOCIAL NETWORKS GENERAL DEFINITION AND CHARACTERISTICS

Social networks may be defined as a collection of individuals who know and interact with a particular target individual or couple.[5] The interactions are the specific exchanges which take place between people; they occur in the present moment.

The literature suggests that the value of the term 'network' lies in avoiding the reification connected in talking about 'community', yet enabling one to talk about a wider set of informal relationships than just the family or the extended kin group. The set of relationships is broadened to include friends, neighbours and work associates.[6]

Some individuals are more socially active than others, for example extroverts more than introverts, which results in size variations of social networks. Other factors which contribute to size variations are level of education, occupation, and income,[7] physical attributes such as attractiveness,[8] relatively stable personal disposition[9], the complexity of social skills,[10] location, and the stage in the life cycle.[11]

SOCIAL NETWORKS: THE FORMATION OF TRADITIONAL SOCIAL NETWORKS

In the last decade research has emerged to address the impact of specific social factors on the social networks of so called target individuals. The three most traditional factors to be considered are class,[12] gender[13] and ethnicity.[14]

More recently additional factors have been examined specifically in relation to more deprived groups. For example, there are studies of the social networks of the elderly,[15] the disabled[16] and injured pensioners.[17] Lastly, there are studies of the social networks of people progressing through expected and unexpected life change or crisis, such as transitions to motherhood,[18] divorce,[19] and transitions through the life cycle more generally.[20]

Although the literature discusses the social networks of the profoundly deaf who are members of the Deaf culture,[21] there is very little on the social networks of people with acquired hearing impairment. It is, in fact, there, but absorbed in general studies of people with disabilities.[22]

Perhaps the paucity of literature on this topic reflects a number of factors. Firstly, the needs of people with acquired hearing impairment are often confused with people who are prelingually deaf and are part of the Deaf culture. Consequently the needs of people with acquired hearing loss have only recently emerged.[23] Secondly, because acquired hearing loss suggests a breakdown in communication, this in turn suggests the incapacity of people with this disability to initiate and sustain a credible social network. Unlike prelingually Deaf people, there is no culture, language, or 'reference group' to fall back on.[24] Thirdly, the concept of 'social network' itself is relatively new in the literature.

THE COMPOSITION OF TRADITIONAL SOCIAL NETWORKS

Traditionally social networks are made up of a certain balance of kin, neighbours and friendships. This also holds true for the social networks of the hearing impaired. It is helpful to differentiate these three terms before considering the case of hearing impaired people.

Kin relations are long - term ties whether or not there is regular face to face contact. Ties with neighbours are face - to - face contacts and often time - urgent as with borrowing small necessities or help in emergencies. Ties with friends have an affective basis reinforced by common interests or experience, and may or may not involve frequent face - to - face contacts.

Given these different functions, as sources of care, kin, friends, and neighbours tend to complement each other in meeting different types of need at different times, rather than being substitutes for one another. However, it is argued that some

substitution does take place in the creativeness of everyday life, particularly in providing psychological support and domestic care.

In the final analysis, it is suggested that kinship ties are qualitatively different from those with friends and neighbours. Although too much emphasis may be placed on the obligatory character of kinship, it remains true that as a source of long - term commitment, kinship ties are pre - eminent. In all major crises, it is to kin to whom people first turn.[25] However, paradoxically, kin support in practice has an unpredictable quality about it and the following factors need to be considered as indicators of who gives what to whom: gender, ethnicity, generation and economic position. A number of researchers (for example, Finch) also suggest that kin may be arranged in flexible concentric circles of closeness.[26] The closest kinship group is distinguished by the frequency of contact and extent of help. By 'flexible' is meant that circumstances change and kin may come in closer or move further out.

Gender also represents a principle through which different treatment is filtered. For example male and female relations are treated differently in many cases even when they both fall into the inner circle.[27]

Until recently, the only evidence regarding networks of people with hearing impairment has come from studies which focus more broadly on disability. It is to these that we now turn to consider how the experience of disability affects the general picture of kinship networks.

SOCIAL SUPPORT NETWORKS WHEN THERE IS DISABILITY IN THE FAMILY: THREE SOCIAL SUPPORT LEVELS

Support networks for families where there is disability appear to require more structure because of the extra stress and vulnerability experienced.[28] Unger and Powell have identified three levels of social support when there is a disability in the family.[29] Firstly, there is the nuclear family, close friends and relatives, and other significant persons. A second level of support includes neighbours, more distant

friends and relatives, and certain professional and service providers. Although less intimate than the first level of support, these sources of help typically have regular contact with the family. A third level of support is still less intimate and is defined by superficial or infrequent contact often in the context of social institutions.

Circumstances alone do not define an individual's support system. The literature suggests that the ability to interact skillfully with others is of greater importance. The success of families seeking social support, in whatever form, will to a large extent depend on their social competence (for example, in articulation of need, arranging reciprocal exchanges, and in responding appropriately when the needs of others change).

However, the tasks of network building cannot entirely lie on the shoulders of disabled people and their families who are likely to be (but not always) in a disadvantaged position to handle them. Some of the specific barriers to social network formation experienced by the hearing impaired will be outlined now.

BARRIERS TO NETWORK FORMATION WHEN THERE IS HEARING IMPAIRMENT IN THE FAMILY

People with acquired hearing impairment are likely to experience more difficulty than hearing people in forming social networks since the disability itself strikes at communication, the heart of social discourse. Scholars suggest that loneliness specifically caused by deafness appears to contain two distinct components; 'social isolation' (that is the result of an apparent inability to sustain and maintain a social network in the outside world), and 'emotional isolation' (that is the inability to be involved and understood by one's immediate family).

Luey focuses on the intensity of the deafened person's feelings which may threaten or repel potential friends especially when they are excluded from the easy sociability which depends on not only the meaning, but also the context and inflection of words, quick repartee, interruptions, jokes, nuances and word play. However,

research has shown that old friends are lost and new friends made during any major life transition.[33]

Despite various barriers to creating social networks, the findings of this study suggest that they may be overcome to a certain extent. This is discussed in the next section.

KINSHIP SUPPORT IN THE SOCIAL NETWORKS OF HEARING IMPAIRED PEOPLE

In general some kinship support could be counted upon by hearing impaired people. However, there was considerable variation in the kind and quality of support given.

KINSHIP SUPPORT IN CULTURALLY MIXED MARRIAGES

The most comprehensive support was provided by Beatrice and Andrew, parents of Gwen. She and her deaf husband, Arthur, formed the 'newly wed couple' in this study. Beatrice and Andrew had previous experience with disability in that their elder daughter, Rebecca, had contracted an arthritic condition not long after she married.

Although Beatrice acknowledged that she and Andrew had not wished to endorse all the traditions from their home, the Isle of Lewis; that of hospitality was one to which they both aspired. Beatrice explained how it was that Arthur's parents, Sue and Rob, spent Christmas week with them for the second year in succession:

> "... Christmas of last year was the first Christmas after (Gwen and Arthur) were married...I said,' I can manage to give everybody lunch,' and (my other daughter), Rebecca said '... I'll do the supper'....and that is what we did..."

Perhaps mixed with the hospitality tradition was an altruistic ideal that people should help people who need help.[34] Also having a joint family Christmas appeared the best way of resolving fantasies, competitive feelings, and doubts particularly when an 'outsider' is married to an 'insider',[35] or from a cultural perspective, marriage occurs 'across frontiers'.[36]

However, Beatrice and Andrew were wise enough to be aware that the giving went both ways and felt it to be a privilege to help Arthur. They were keenly aware of Arthur's need to achieve a level appropriate to his formidable intellect and literary ability.

Although Beatrice and Andrew willingly gave their encouragement, strict boundaries were observed to avoid the danger of over involvement or enmeshment.[37] Beatrice related:

> "...The choice(s) must be...(theirs, and) Arthur likes to talk to Andrew about (things)...he'll consult him on the wording of a letter,..since Andrew has been through the university system...as well as Gwen, Rebecca and Geoff..."

'Enmeshment' or its opposite 'disengagement'[38] are often psychological threats to families where there is a disability. It may be asked how this couple managed to keep such a clear sense of appropriate boundaries. Beatrice pointed to her friendship circle as being helpful:

> "...We've always been fortunate in our own friends; and so we have a wonderful circle of friends..."

Discussions with close friends helped Beatrice and Andrew maintain their objectivity, equilibrium, and sense of mastery or control when faced with family disability.[39] Gwen, however, appeared only aware of her parent's acceptance and identified with it. She related:

"...(Perhaps)...the way...(my parents) brought me up has meant that they can cope, and I can cope with...(Arthur) (and) his deafness..."

Gwen reflected a sensitivity to what Krebs calls a 'subterranean nexus of reciprocity'.[40] Because her parents were caring compassionate people, she was also. She went on to describe her parents' initiative in attempting to learn BSL.

"...My father's...shy so he's...wary of using Sign, but he will finger spell if he's...(repeated without Arthur understanding) ...My Mum Signs a bit more...(as) she's an extrovert."

Although Gwen implied that personality is one factor in willingness to use and learn BSL, the primary issue is seen as one of acceptance.[41] For both Gwen and Arthur, this gesture was symbolic of her parents' acceptance of Arthur and Deaf people generally.[42]

Andrew and Beatrice's BSL initiative could also be seen as a symbol of 'intergenerational solidarity'.[43] Three key factors composed the solidarity that existed between Andrew, Beatrice and Arthur. The first factor is 'association'. The more Beatrice and Andrew associated with Arthur, the more solidarity existed within the relationship. Within the literature, association has been typically defined as close interpersonal contact and residential propinquity. A second factor is 'affection'. Bengston and his colleagues argue that helping behaviour is the key signal to affection within a relationship and the giving of help is the crucial element. The third factor related to family solidarity is a certain mutuality of values, beliefs and opinions. Any behaviour that aided this'consensus' promoted solidarity. Since Andrew, Beatrice and Arthur had similar values regarding education, religion, and equal opportunities, a common value base truly existed.

Although Arthur acknowledged that he had never felt so much acceptance, communication was difficult with Andrew. Arthur recalled:

"...when...my father-in-law Signs, he is very stiff...(and) he keeps Signing to a bare minimum... I think he feels more comfortable with finger spelling...he's (also) very difficult to lipread...because he's got a very strong Scottish accent."

Gwen too recounted communication problems, but more with her mother.

"...Mum found it very difficult at first...if we were talking (in Sign) and I'd switched off my voice. She would forget that we were talking...She would talk to me and then she'd be upset because I didn't answer because I was talking (using Sign with Arthur)..."

Gwen's sensitivity to linguistic exclusion was understandable as she had found it difficult as a child to hear her parents speak their native Gaelic, a language she was never taught. While visiting Beatrice and Andrew during the Christmas holidays, Arthur's parents made the following remarks about living with a hearing family:

Rob:

"...it's hard,..you don't know what (the family) are saying."

Sue:

"... Sometimes Gwen talks (without Signing) to her parents, but it doesn't worry me. Sometimes Gwen tells me what it is."

At this time Arthur's parents were also Gwen and Arthur's neighbours. Such close proximity could make the relationship a powerful instrument for informal care as illustrated in studies of working class families.[44] However, unless an element of 'choice' was experienced, there was danger that the relationship would deteriorate into one of obligation and enmeshment.

Arthur felt his parents, specifically his father, had been socialised into feelings of dependence and powerlessness and that his father perceived himself as not having the cognitive competence, psychological skills and support systems needed to influence his environment successfully.[45]

Barbara and Ben provided another example of intergenerational solidarity as they had worked hard from the beginning to consciously eradicate any condescension in her husband's family. Barbara felt her best advocate was her own attitude. She explained:

> "...Often in (my) marriage (my) positiveness makes it fairly easy for my relatives to accept me. (For them), I am probably a force to be reckoned with,...well I am not a 'poor little thing'...there are difficult situations such as large family gatherings...and I don't hear everything that is said, but that happens everywhere."

Barbara was reluctant to make traditional English assumptions concerning the reliability of female kin support.[46] This was not because of a lack of trust, but rather that 'the care' provided would stifle her ambition and drive, personal characteristics which she valued above all others as they had been carefully fostered by her Australian parents.

Although Barbara did not present kin as useful for social support, she did value their companionship on holidays. Unlike Arthur and Gwen's 'at home' family holidays, these were abroad. Barbara recalled:

> "...we went to Brittany for two weeks... beautiful weather. My sister and her four children, my mother, my father-in-law...it was a big family party...lovely."

Barbara first presented her holiday as a rosy success, but later she revealed that there had been difficulties. However, she was still able to help. She remembered:

"My deafness on holiday was an advantage. (Two) car(s) broke down so I volunteered...to look for a garage...(There) they were all set for me to phone for...(one) in French! So I said, 'I'm terribly sorry, I am deaf and cannot use the phone...would you be very kind and make the telephone call?'...(which they eventually did)..."

Kinship support also emerged as a factor for elderly people, specifically Max and Theo, a widow and widower (see Chapter XII). The next section will focus on the 'caring' services provided to Max by his family.

KINSHIP SUPPORT FOR ELDERLY HEARING IMPAIRED PEOPLE

Before discussing Max, the literature with reference to loneliness and the elderly, will be examined. It emphasises that elderly people are not as lonely a group as sometimes supposed. It is probably true that the amount of social contact declines with age,[47] but actual levels of contact are not considered to be the crucial factor. Rather it is more important to consider the gap between achieved and desired levels of contact. It may be that the desired level of contact with other people drops as rapidly as actual levels of contact, thus protecting older adults from loneliness. The other factor which emerged is that the contacts which the elderly do have are usually of a higher quality than when younger thus providing more satisfaction.

However, Clark and Anderson believe that the most critical factors regarding loneliness and elderly people are whether or not they have a confidant and good peer relationships.[48]

Contact with kin is another factor attributed to keeping loneliness at bay for elderly people. Arling, in his study of American widows found that lower levels of loneliness are not related to visits from children, but are related to greater contact with friends and neighbours.[49] While contact with family members may persist, there is no guarantee that it is enjoyable. Rosnow argues that frequent contact

between elderly people and their children often becomes ritualistic, based on obligation rather than warmth or closeness.[50] However, it could also be argued that feelings in more fixed societies than the USA, are even more deeply held behind seemingly ritual and conventional behaviour.

Bearing this in mind, it was not surprising to find Max, a distinguished educational administrator with no previous history of hearing loss, fighting to hold on to the remnants of control and independence. Now in his early eighties, he found himself retired, widowed, moderately hearing impaired and isolated to a certain extent.

As with the example of Arthur and Gwen and Gwen's parents, 'care' took the form of respectful concern. In this case, however, the informal care managers were Max's two daughters, Margaret a social worker and Esther a teacher.

A combination of accident and design meant that Margaret and her family lived a few houses down the street from Max making her a neighbor as well as kin. Therefore there were more opportunities for care exchanged between them to be informal, reciprocal, and sometimes enjoyable. This state of affairs was strongly endorsed by Max who needed to be continually reassured that he was not a burden.[51] Nevertheless, There were certain difficulties with communication. Margaret gave an example:

> "At the table (my father) will sometimes say, 'Are you speaking to me?' And I say, 'No, not at the moment'. And I feel bad about it because I feel he's not included...even in the circle of five of us eating together...unless we speak directly to him..."

It is well documented that 'the dinner table', the symbol of family togetherness and the primary forum for the socialisation of children among middle class families, may become a symbol of isolation and even alienation for many hearing impaired individuals.[52] Max's family was certainly aware of the problem as Margaret's husband, Colin, recounted:

"...(Max)...likes to know what's going on like most of us do...he feels excluded because you're not always conscious of his deafness,..because when (we're) having a conversation, we tend to...drop our voices...and we talk about something that has happened between the two of us, which really isn't for his ears anyway...(maybe something quite trivial)...but then he says, 'what's happening?..(or) 'Am I missing out on something?'"

Although Max's family did amazingly well in caring for him on a practical level and to some extent on an emotional one as we shall see, these examples highlighted the problematic paradoxical heart of the matter with many English families and their elderly hearing impaired relations. Max knew implicitly that English middle class domestic norms dictate, by way of their conversational style,[53] that feelings of 'belonging' are generated by unstated meanings and being privy to the mundane details of everyday domestic life. When a hearing loss prevented their absorption, the situation became more complex because of the traditional English dislike of 'repeating' unless a subject is really important.[54] To this is added the fact that there are enormous ambiguities involved in sensory impairments generally making it difficult for caring relatives to respond appropriately. For example, how does one know whether or not a hearing impaired relation has heard something? Conversely, there is no ambiguity when an elderly relative is in a wheel chair as everyone knows it requires pushing.

It was for these reasons that the hearing impaired people in this study were not closer to their kin. In the next section, illustrations are given where kin were overtly hurtful in that they had left the hearing impaired person feeling fearful and inadequate rather than supported.

WHEN KINSHIP BECOMES UNHELPFUL, HURTFUL AND/OR CONDESCENDING

It became evident that ambiguities involved in a hearing handicap may in fact result in mistreatment by kin. For example, Joe (aged 64) who had been partially deafened at the age of two by diphtheria reported the following incidents:

> "(When)...I...(was)...a child (of) eleven,..My mother had a cousin of about 19...(who) used to tease me...(as) I couldn't pronounce my 's's'...I used to say 'Yeah' (instead of Yes). But a child of that age feels...(hurt by such criticism). Then my mother had another cousin. We were a group in a family...and I started to say something, and they were listening to me and I was talking with my hands...And (this cousin) said, 'stop talking with your hands. Put your hands under your thighs', which I did and I stopped talking,...(and ever since) I've always worried that (I was) going to make a fool of myself in company..."

Indeed, some of Joe 's first attempts to form his own social network were blocked by insensitive older relations. Joe also had difficulty with his parents whom he felt never really understood his communication needs, nor were they able to help him articulate them to others.

A somewhat similar story was told by Henry. He recalled his relief when both his children were pronounced free from hearing loss:

> "...it was part of (my social) conditioning...a lot of it was my relations thinking I was not (a good marriage prospect)... because of my deafness,..and some of them had the...idea that the handicap might be hereditary...(It deeply affected me and is connected with the fact that I did not marry) until my late thirties...I know that when Clive was tested in our house in Norfolk, I felt a great sense of relief that everything was all right."

These two examples illustrate the enormous importance of an accepting kinship network for hearing impaired young people when they begin to reach out to make their own circle of friends. Because of these early humiliations at the hands of relations, both Joe and Henry had to struggle with what calls 'the invalid mind', which develops when people who have been disabled early in life are treated as inferior and consequently develop deep feelings of inferiority.[55]

Yet because condescending attitudes are so prevalent, changing them is of necessity a difficult long term process. Barbara calls this process 'converting the environment'.[56]

However, time didn't always make a difference, for example, Julia's parents stubbornly opposed her commitment to Sam. Although she loved all her family, she was proud that she and Sam had kept their independence from them.

KINSHIP SUPPORT WHEN THERE ARE GEOGRAPHICAL DISTANCE BARRIERS

Two deafened people in the study had migrated from other countries, Nigeria and the United States, so that the distance factor was in fact very great. Both people, a man and a woman, had extroverted personalities and were in high status professions which undoubtedly affected their attitudes and determination to keep in touch with their roots. They seemed to see the distance between England, their resident country, and their country of origin as a challenge rather than an obstacle. Although maintaining contact was hard at times, both had succeeded in doing this through telephone calls, letters, and visits. It was of interest that the network of the Nigerian, Anthony, was dominated by kin while the network of the American, Rachel, was dominated by friends. They also both succeeded in actively building networks in the UK.

Anthony had not only kept his network, he had also sustained his high status within his family.[57] He explained:

"Before decisions are taken in Nigeria on major issues, my family must consult me in writing and wait for my reply. They (have) followed whatever I say up until now...the realisation of my responsibilities as someone interested in my family makes me struggle harder."

Anthony was the eldest of five brothers and sisters. Although he remembered his family as expressing great sorrow when they were told of his deafness, they nevertheless remained loyal. This suggests that in a fairly fixed society such as Nigeria, if a person has a high profile role within their family when they are disabled (deafened), they will keep this status provided they are perceived as carrying on their family duties and responsibilities.

When reviewing the two families discussed most often in this chapter, it was the mothers, Beatrice and Margaret, who were most dedicated in their attempts to care. Fathers had more of a 'watch dog' role, making sure their wives didn't over do it thus endangering the equilibrium of the rest of the family.

Since the gender factor appeared to have relevance in looking at the kind of care given, it will be examined further in the following section.

CLOSE KINSHIP SUPPORT WITH REFERENCE TO GENDER

Gender has been called a prism through which all of our lives are lived. It is ever-present and yet taken for granted. It affects the language we use, the way we move, and our conception of relationships.

Women generally are more involved than men in social support. This is thought to be a matter of necessity rather than choice based upon the division of labour in our society. While both men and women may now go out to work, women on the whole have retained domestic and caring responsibilities for which they need the support of others.

MOTHERS AND FATHERS

The literature suggests that some women devote much of their lives to kinship support.[61] Besides the mothers already mentioned, there were two others who might be called 'rehabilitation mothers'. They were women who had experienced tragedy themselves, had survived it, and therefore knew how to bring others through similar experiences of traumatic loss. Sam recalled how his mother responded when he was deafened at aged 17.

> "... she put up with me...I suppose to begin with I was very moody and she was very patient and very supportive... she made me get on with my life. She did not let me stay in bed all day."

Sam's father had been there, but was less helpful because of an ingrained attitude of pessimism. Sam eventually recovered his equilibrium and went on to become the first member of his family to complete undergraduate and post graduate education. Perhaps partly because of his mother's support at the critical time, Sam was prevented from developing the 'invalid mind' described earlier. Other people in the study were less fortunate. Joy recalled her mother's response at the time when she and Mike had to temporarily move back into the parental home after she was deafened by meningitis:

> "...I never really got on with my mother...and she didn't really take to my deafness...She was quite friendly in her way,..but she would ignore me every now and then...(and) she turned to my sister...and I felt a bit left out...whether it was me or my deafness (is not clear)."

Although Joy was unlucky with her mother, she was extremely fortunate in her husband, Mike, who managed her recovery in a not too dissimilar way as Sam's mother had done for him.

The above examples demonstrate a certain unpredictability surrounding kinship support. Finch suggests that kinship support is rarely possible to predict simply from knowing that one has a mother, a brother, or grandchildren, or what assistance, if any, is to be given at present or in the future.[62] Assistance is often given, but how much, from whom, and of what quality is not predictable.

SIBLINGS

Sibling relationships are similar to that of parents and children in that both are ascribed.[63] They are perceived as different from these relationships in two important ways Firstly, although support does pass between siblings, it seems less reliable, in the sense that whether it is offered, often depends on personal circumstances and personal liking. Secondly, sibling relationships tend to be much more obviously built upon reciprocal exchange between two people who are in equivalent genealogical positions. In both respects the relationships bore a closer resemblance to voluntary friendship than to kinship.[64]

Rivalry and competition also appear to be major functions of sibling relationships in adolescence as it is thought to be helpful in preparing for later competition and to build character.[65] Allan did not find any evidence that sibling rivalry continued through the life span, although it could arise on occasion.[66]

Both sisters and brothers were mentioned as being helpful by hearing impaired people in this study. Moderately deafened Martha (55), a member of a large Irish family, described how one sister helped:

> "I can understand my sister on the telephone because she knows...I'm deaf and she speaks up...you see I haven't got confidence in anybody (else)...only my own people..."

Martha drew a strong social boundary around her female kin calling them implicitly 'special',[67] as they were the only ones she could 'hear' on the telephone.

But siblings also had the power to hurt. Frank, a geography professor in his sixties, related the following incident:

> "...(my sister) occasionally has...(referred to my) deafness... (at a dinner party)... (She will say), 'Oh,..(my brother's) deaf you know'. At that moment, it hurts, but then I forget it..."

Frank's wife, Simone, put his sister's tactlessness down to latent sibling rivalry.[68] She said:

> "...I think there has always been a sort of jealousy (that Frank's sister is) not conscious of. Frank has always been his mother's favourite...and he was the one who academically succeeded and she didn't..."

Sibling rivalry and a feeling of 'difference' emerged in the relationships of two other sisters. Joy recalled her feelings about her only sister:

> "I have one sister... we just keep in touch really. I wouldn't say we were very friendly...yes, she's accepted my deafness... (but) I don't think she would be a friend if she wasn't my sister..."

Anne, who had only recently been diagnosed as hearing impaired, was unsure how her sister would respond to knowledge of it.

> "...I would describe my relationship with my sister as 'friendly' at this point...(we) don't have those opportunities to talk that we had before (we married)...she's quite different from me in an awful lot of ways."

This new vulnerability in Anne's life might draw her sister closer, but this was doubtful since Anne perceived them as being so different. Joe's sister's story was told by his wife, Sarah, as Joe himself was too moved to tell it:

"...Joe's...sister is in a psychiatric unit...She tried to come out this year, but...couldn't cope. I went to see her to help her talk about how she couldn't cope... it was a classic case of someone who'd been institutionalised..."

This was the most extreme example of the complete breakdown in what might have been a supportive relationship between sister and brother. Where both siblings were hearing impaired, the relationship was more complex. Theo (84) recalled what outings were like with her much younger sister.

"We went up to Derbyshire...but I realised that I must not talk...I can't say 'Oh, look at this, look at that'...because then she turns around to see...(and we'd) be in a ditch..."

Although Theo was ambivalent, her relationship with her sister was an active one with many reciprocal aspects. Sarah mentioned how her brother's attitude changed towards Joe's deafness:

"...When...(my brother) first met Joe, he understood about the difficulty, but...he didn't empathise at all because he was (physically) ok. Then he became diabetic and his whole attitude has changed..."

Thus, Sarah's brother's illness helped him to become sensitised to Joe's need for repetition. Barbara's brother was also helpful as husband Ben explained:

"...Barbara's brother is very good at...(interpreting the television), but he has had many years of practice at it,..(as) it is really quite difficult to listen to something and tell somebody else about it..."

Barbara's brother is the only example of a male interpreter. This role is usually taken by women whether relatives or friends.[69] It was likely that Barbara's younger

brother felt more responsibility for his elder sister since their father had died. He, like Sarah's brother, had become 'wise ones'.

When looking at the findings through gender lenses, men appeared to be almost as involved in 'care' as women in providing companionship, interpreting skills, help through crises and transitions. This support was rarely asked for or negotiated, but occurred as a result of the development of informal coping strategies by kin who were concerned about the quality of life of their hearing impaired relative. Although further research is needed here, it may be that men are involved to an unexpected degree because what they provide does not feel like traditional 'tending' care to them, but rather like some form of communication.

SUMMARY

Hearing impaired people in this study found support in a wide variety of social relations with their kin. The most successful appeared to involve some sort of reciprocal arrangement. There was also a strong unpredictable element in the kinship patterns especially among sisters.

A major difficulty confronting kin in this study was the problem of interpreting and understanding the ambiguous nature of the needs of their hearing impaired relations, and consequently being able to provide appropriate care. In most cases hearing impaired people themselves did not have the confidence or desire to explain their communication requirements in detail even if they understood them. It was felt that sharing such details did not belong with their kin, but more with spouses or voluntary friends where there was more genuine affection.

The reluctance of hearing impaired elderly people to be more explicit about their needs may be partly explained by their awareness that they run counter to prevailing domestic norms in many English families. While it is not necessarily always the case, feelings of 'belonging' and 'cohesion' have traditionally been generated orally and indirectly through the easy sharing of domestic sociability in a way in

in a way in which hearing impaired people can not join. Repetition is therefore needed. However, here is where the paradoxical heart of the problem emerges. It may be that in the context in which these people lived, social norms dictated that these so called trivial conversations with unstated meaning are not considered important enough for repetition. As we have seen, it is extremely difficult for hearing impaired people not to feel that it is they who are unimportant, and they, therefore, become caught 'between two worlds': those who hear and those who do not.

It appears to be the case that education and counselling are needed to help families expand their understanding of appropriate responses so that care and concern for their hearing impaired kin is expressed more effectively. Hearing impaired people themselves also have the responsibility to learn to lipread and to increase their skills in reading nonverbal cues and body language. Without these interventions, the present community care policy where families play such an important part, will be of limited value for elderly hearing impaired people.

On the whole women seemed slightly more involved in supporting their hearing impaired relations than men, although men were much in evidence either as 'watch dogs' or in direct help through repetition, interpretation, companionship etc.

Generally if kin relationships were unsatisfactory before the hearing impairment, they remained so afterwards. There were no examples of the hearing loss 'cementing' a formerly uncertain relationship.

Evidence provided by the hearing impaired people in this study suggested that geographical distance from kin could act as a communication challenge rather than barrier provided relationships had been strong before the distance existed. The next chapter will complete the social network picture by focusing on friendship networks.

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CHAPTER XI THE IMPACT OF HEARING IMPAIRMENT ON THE SOCIAL NETWORK: FRIENDSHIPS, PROFESSIONALS AND RELIGIOUS INVOLVEMENT

INTRODUCTION

Having considered kinship, let us now explore the impact of hearing impairment on friendship, relationships with professional helpers and associational groups, especially churches. In doing so, it is important to remember that categories such as these are not mutually exclusive: there were examples of kin who were also friends and professionals.

Abrams argues that beyond close kin, "our strongest bases of informal social care are those of non - located moral communities associated with churches, races, friendship groups and certain occupational groups - not neighbourhoods."

It will be suggested that hearing impaired people, have considerable difficulty establishing or mobilising a social network of friends because of the communication barriers which their hearing difficulties are likely to present as there is a basic note of dissonance between the voluntary nature of friendship and the implications of being hearing impaired.

In this chapter an examination will be made of the impact of certain psychosocial factors on the formation of social networks for example class, gender, ethnicity, old age, and disability

Let us analyse these difficulties using Unger and Powell's three levels of social network formation: the first level is the nuclear family, close friends and relatives; second, neighbours, more distant friends and relatives and certain service providers; and third, the still less intimate defined by superficial or infrequent contact often in the context of social institutions.

Within this model, there will be an analysis of old and new friendships, responsibility for network formation, the two primary strategies needed when conversing with a hearing people specifically 'looking' and 'repeating', and the role of helping professionals generally.

Lastly in an expansion of our understanding of the third level of social support, there is a discussion as an example, of the role which church involvement has had in the lives of its hearing impaired members with a specific focus on tradition, fellowship versus solitude, the inductive loop system and belonging, and the support of the clergyman and his church.

The specific nature of friendship will first be discussed. The ambiguity surrounding this concept requires a comprehensive discussion in an effort to capture its core meaning.

THE NATURE OF FRIENDSHIP

The conventional definition of friendship is that of a freely chosen, voluntary and predominantly expressive relationship.[3] While there are certain norms and conventions which pattern friends' behaviour towards one another,[4] friendship of itself is not seen as being incorporated into the institutional fabric of society in the way that kinship is. Certainly, not all societies foster or tolerate the freedom and flexibility that is a typical feature of British friendship.[5]

Within the literature, some attempt has been made to define an idealised version of friendship sometimes known as 'genuine' 'real' or 'true' friendship. In these ideal friendships, the solidarity of friends, based solely on their personal and voluntary commitment to each other, is taken to be unfettered by any selfish or instrumental concerns. From this perspective, such friendship can be recognised as a bond of enormous moral significance, as one of the highest expressions of voluntary altruistic commitment there can be between people.[6]

The literature, however, makes the point that such ideal relationships are rare and may more nearly resemble a concept of 'best friends'. The pattern usually found is a range of relationships which combine in different ways the various elements that are entailed in the general notion of friendship. This appears to be the case not only in straightforward behaviour terms (for example, when friends meet and the types of activities undertaken), but also with respect to the level of intimacy, trust, and commitment experienced.

Despite the complexity surrounding the concept of friendship, it is agreed that it is a voluntary relationship in that the ties are chosen quite freely and may be ended as desired. However, friendship is often a little less free than it appears. For example, many friendships originate between people who are involved with each other in formal organisations of some sort, which have some effect on shaping their ties. However, the extent to which they will recognise their relationship as one of friendship will depend in part on the extent to which they see them as free of organisational constraints.

Finally, one of the foremost features of friendship is that it is essentially a relationship of equality. In other words, in addition to being informal and free from broader structural imperatives, friendship is a bond in which issues of hierarchy and authority have no bearing. Therefore, it would be expected that the majority of friendships occur between people who occupy broadly similar social positions. There is of course, nothing within the notion of friendship itself that requires this to be so, but the economic and social divisions within the society certainly encourage it. In other words friends are normally of roughly the same age and class position. They also tend to share similar domestic circumstances, to be of the same gender, to have similar ethnic backgrounds and, where it is of social consequence, to belong to the same religion.[7]

THE IMPACT OF PSYCHOSOCIAL FACTORS ON SOCIAL NETWORKS

Let us now consider the psychosocial factors which may make an impact on social networks.

CLASS

Studies have shown that working class people have fewer friends than their middle class counterparts, and that the contexts in which interaction with their friends takes place are more limited.[8] Bulmer suggests a reason for this may be the part which the home plays in developing and sustaining non - kin relations. Middle class people typically foster friendships with new acquaintances by inviting them to, and entertaining them in, their own homes, thus broadening the relationship beyond the original setting in which they met.[9]

Conversely, working class people tend to compartmentalise relationships in the context in which they first develop; for example, work, common recreation, locality, and are not extended into the home. Thus these relationships do not rest upon friendship, but rather upon relationships between 'mates' for men, and group sociability for men and women.

In summary, it may be said that middle class norms dictate the relationship to be of the most importance while the working class model of friendship places more emphasis on the place where the relationships develop.[10]

GENDER

Although a less traditional factor than class, the importance of gender in social networks is crucial as we have seen. Bell even argues that gender is the most pervasive feature in shaping friendships patterns today.[11]

Friendships among men tend to be largely connected with notions of male identity resulting from their socialisation patterns. Given the dominant paradigm of masculinity where emotion is disparaged, it is understandable that ties of friendship between males are based upon sociability rather than intimacy. Conversely, there is usually no incompatibility between being intimate and feminine gender identity.

It is evident that a good proportion of some couples' closer friendships are couple - orientated. Yet this does not necessarily mean that friendship ties between the four of them are equivalent or equally strong. In some instances this may be so, but culturally the expectation appears to be that the closest relationships will be between the two males and the two females rather than cutting across gender boundaries.

ETHNICITY

Another factor affecting friendships especially in inner city areas is ethnicity. This is particularly true for people from the West Indies and the Asian sub-continent. As they have settled, and the second generations have grown up in the same general locality, they have developed their own networks. Migrants commonly wish to go to places where compatriots, particularly kin, have led the way, in the same way as siblings sometimes join each other in new towns. Once settled, ethnic minorities generally tend to stay put thereafter because of the support and protection they receive from local ethnic institutions and cultures.[12]

OLD AGE

Although all stages in the life cycle are likely to bring about the dissolution of some friendships, and the formation of new ones,[13] there is specific interest in the elderly because the majority of people who have an acquired hearing loss are in this stage (see Chapter XII for exact numbers).

Studies suggest that elderly peoples' friendships are rarely passively dissipated as sometimes implied, but are altered and changed in accordance with the overall status.[14] Other things being equal especially health, elderly people are involved in an active reconstruction of their friendship networks in ways shaped by the freedoms and constraints of their current situation, such as their immediate social environment or personal space.

DISABILITY: THE THREE LEVELS OF SOCIAL SUPPORT REVIEWED

Researchers suggest there is a need for three levels of social support when there is disability in the family.[15] Although each of the levels overlaps with the next, these differing degrees of intimacy require somewhat different interpersonal skills. For example, the first level of support, the nuclear family, close friends, and relations, relies on what has been called the consensual norm, while the second level of support, neighbours and more distant friends and relations, is based more on a norm of reciprocity. The third level of support is more distant and may rely on institutional or professional obligations.

The next section will refocus on the first level of social support with reference to close friendships.

HEARING IMPAIRMENT AND OLD AND NEW FRIENDSHIP

The literature suggests that acquired hearing loss especially of a severe or profound degree, is likely to make one lose some friendships.[16] The people in this study presented a more complicated picture, suggesting that additional psychosocial factors were operating specifically gender, class, and personality.

Sam deafened at 17, was the one person in the study who believed he had lost friends, and wished he had more in the present He recalled:

> "...(when) friends come to visit,..they...talk to Julia (as they are her friends)...I will...talk to perhaps one other person...(in the group),..(the topic of our discussion) might not be the same as everyone else is talking about."

Although Sam's shy personality and profound hearing loss undoubtedly slowed down his ability to make friends and limited his pleasure, there were also other factors. Firstly, Sam and Julia had moved to their present house from the North only two years ago. Moves are well known for disrupting social networks and are especially difficult

to rebuild if one is hearing impaired.[17] Meeting strangers can be a particularly uncomfortable task since one's social skills often feel depleted.[18] Sam recalled:

> "I had more and better friends at Leeds University where people didn't 'pigeon hole' you as they do in my present job. They were more open minded there...perhaps the (university atmosphere) helped."

Sam felt that his present work environment was not conducive to his growth intellectually in the way of a stimulating career or emotionally through involvement with colleagues/friends. An aborted friendship with a deaf colleague, had confirmed that differences beyond the common factor of deafness could be too great. These experiences contrasted sharply with pleasurable times he recalled with members of his Sub-Aqua club at Leeds:

> "I particularly enjoyed my friends in the diving club...it wasn't so much the common interest, but the fact that we all drank together afterwards...I don't feel I have that sort of experience...(now)."

Sam was able to transcend both his shyness and deafness by the 'warming up' process of drinking in a pub. The pub atmosphere was likely to feel more congenial because of his working class roots.[19]

Gender was another factor as Sam believed it was much easier to make new acquaintances with women rather than men. He recalled:

> "With...women especially, I can understand what they are saying even if they...don't know I am deaf;..I don't think a man has as much patience as a woman...perhaps it's not just patience...it's more understanding of the other person."

However, deafened people have other requirements for effective communication and Julia gave an example:

"...(While) a woman will get more upset or angry if you don't understand the first time,.. a man is likely not to be so bothered by (having to repeat)...Remember... John? He used to talk to you a lot,..(and) I never once saw him get angry or impatient...(at having) to repeat himself..."

Sam then recalled his friendship with John more fully:

"...in Leeds, I...shared a house with a friend and his wife... (John,) would talk to me, and it never bothered him if I misunderstood something...(He would)...either repeat it or explain it in a different way..."

Not only did John have a high toleration for repetition perhaps having some appreciation of it's helpfulness in a more general sense,[20] he had also acquired the art of paraphrasing.[21] Thus Sam's current isolation was not because of lack of effort as he circulated widely. For example, recently he had enrolled in a French class, helped a friend restore his cottage in France, and taken part in a sailing club for the disabled. He had no desire to go to a Deaf club although he had attended them in the past and even taught at a school for Deaf children.

Sam had discovered that he was 'too hearing' in his thinking to feel comfortable in the Deaf community.[22] Also, living with Julia who was both hearing and middle class, meant that she took charge of their social life by writing letters, making telephone calls, and interpreting in social situations. Sam recalled:

"I used to write to...(family and friends) when I was at college on my own, but...I've let it drift and I don't write very much."

Perhaps Julia had colluded with Sam in creating his social dependence.[23] However, it was not intentional as Julia simply saw her social skills as a reflection of her gender,[24] and that the process of Developing Mutually Enhancing Networks (DMEN) was a sensible strategy for everyone, hearing or deaf, as it guarded against emotional isolation and intellectual stagnation. Despite their many moves, Julia and Sam's joint

network had in fact become quite extensive consisting of over forty relatives and friends when formalised on paper.

With this couple, the factors of personality type, class background and gender were more significant than deafness in causing Sam's personal isolation. He had assimilated enough into the middle class hearing world to make a certain peace with it.[25]

Joy found herself in a similar situation to Sam's. However, she had been more successful in holding on to her old friends. This was largely possible because she and her husband, Mike, unlike Sam, had returned to their childhood home. She recalled:

> "...I've kept all the friends I went to school with...(those since we got married)... and then there's all the (new) friends around...since we've moved (back)..."

Despite her working class roots, Joy adopted what might be called a middle class manner of relating, for example old friends were substitutes for kin.[26] Contrary to the literature,[27] Joy's experiences suggested that hearing loss need not deplete one's social skills. The fact that she was able to pick up with old friendships in an easy manner implicitly revealed that she was known to have the qualities of a good friend. She explained:

> "Some...friends...I've made since I've been deaf...As a matter of fact, (I'm going) to my friend's place tonight...I was around last week and before...we went out on a Saturday...I made (these) friends,..not Mike,..he didn't know them."

Autonomy in friendship making and maintaining[28] was very important to Joy. Since the literature suggests that people going through identity and life changes,[29] as well as those who are suddenly disabled, specifically deafened,[30] do lose friends, it was of particular interest to see how Joy kept hers. She appeared unconscious of any strategy. She remembered:

"...I had to tell...(my old friends) to speak slowly, please; and I suppose they see how Mike speaks to me, and they do the same...they can see that I am still the same person..."

Because Joy had an understanding husband and loyal old friends, she could build on these relationships and go on to establish new friendships. Also Joy had no difficulty making appropriate disclosures about her deafness. She actually appeared to be informing or educating her old friends rather than 'disclosing'. Perhaps her skill here was a reflection of the fact that she was completely free from any sense of shame connected to her sudden loss of hearing,[31] although she did feel a certain sense of devalued status sometimes connected with being a member of a minority group.[32]

Since most people with acquired deafness have already established marriages, families, careers, leisure and social activities, it follows they would be inclined to maintain these life styles.[33] While some people experiencing traumatic hearing loss might have to go through a period of isolation and withdrawal, closely associated with grieving, Joy avoided this behaviour and continued in her easy capacity to keep and sustain friendships. However, she did not always meet with success. Mike recalled:

"...it all depends whether other people are willing to make the effort...some people won't,..(like) Pat over the road...(she and her husband) are nice enough people...they'll say good morning and all that, but they won't say much else to Joy..."

Mike pinpointed what appeared to be a classic encounter between a hearing and deaf person.[34] He saw the problem as one of embarrassment in that their neighbor didn't know how to talk to Joy. We do not know what was behind this neighbour's anti-social behaviour, but Joy had her own opinion:

"...there are always some people...that just can't accept...and they've no idea how to...talk to me...(Pat) won't talk to me when I'm alone..."

Although Joy admitted to some frustrating encounters with neighbours as confirmed by Sainsbury,[35] she, like Sam, discovered there were compensations specifically in cross gender relationships. Possibly cross gender friendships are a particular feature of couple friendships when one partner has been deafened provided the couples involved have acquired the security and mutual understanding with one another to allow for its development.

Sussman suggests that a trait of people who have come to terms with their hearing loss is their capacity to socialise with other hearing impaired people.[36] Although both Joy and Sam had links with NADP (National Association for Deafened People), neither claimed a good friendship with another couple like themselves. This may have left Joy and Mike with a certain sensitivity about their life being particularly hard. For example, Joy recalled:

> " We don't know any other Deaf couples so we can't compare their (situation with ours)...we know plenty of hearing people, but obviously it is different since they can communicate a lot easier than we can."

Returning to Julia and Sam, Julia's calm organised approach towards her and Sam's social network was a direct contrast to the more anxious attitudes of some of the hearing wives in the study. In the following section, an attempt will be made to consider their concerns.

SOCIAL NETWORKS: WHOSE RESPONSIBILITY ?

Three hearing wives in the study were anxious about their responsibility for 'social network' formation. The most articulate was Joe's second wife, Sarah. As we have seen, Joe's early attempts at developing a social network were thwarted by his own kin and then by his first wife.

Now Sarah wished to help him by explaining her understanding of the term which focused on friendship for relaxation and intimacy more than enjoyment and sociability. While it is possible to have both, there was the implicit suggestion that the gentleness

of Sarah's feminine network appeared to be more appropriate for Joe at this time while he was gradually breaking free from his former isolated marginal life style.[37] Joe, on the other hand, was mildly resistant to this arrangement as it was 'women's talk'. Recent linguistic studies agree with him.[38]

To a certain extent, Joe had compensated for his isolation by becoming a workaholic. Because Joe had lost his wife and sons through divorce, his sister through mental illness and his parents through death, it seemed that for a time he lost trust in close relationships generally as they had only brought him sorrow. Although Joe was appreciative and admiring of all Sarah's efforts to build a friendship circle, he was also aware that his enjoyment level was not quite 'in tune' with hers. Joe explained his attitude:

> "...My idea of a dinner party is conversation (not nattering),..that you talk about things,..but when your hearing aid is just picking up other people's talking...which makes it difficult to concentrate on your next door neighbour,..it gets a bit frustrating."

Joe's deafness meant that he could not converse at Sarah's dinner parties in the manner that he would have liked, but also he was disappointed in the general tone of the conversations that he could hear because topics of 'true' consequence were not discussed.

Sarah, on the other hand, was pleased because she had succeeded with the strategic process of (DMEN) Developing Mutually Enhancing Networks. However, she continued to be anxious at what she considered to be Joe's dependence on her for his social life as she was unaware that husbands are often dependent on their wives in this way even when they have perfect hearing.[39]

Gwen, Arthur's wife, also had a strong sense of responsibility concerning their mutual social network. Like Sarah, she had no experience of men's social networks, for example, she did not understand why Arthur did not need a 'best friend' in the way she did. Arthur, like Sam from a working class background, found his friendships in his

'mates', which were context based.[40] Gwen was able to acknowledge that her anxious attitude about Arthur's friends was more in connection with her own fear of taking friendship risks. Nevertheless, this sense of responsibility gave her additional courage to do things which she might not have done otherwise.

As a bicultural couple, Gwen and Arthur's social network was drawn from both Deaf and hearing communities. Although a larger catchment area, integration had to be worked at gently, but was eventually successful on both sides as a result of the quality of Gwen's friends, her personal sensitivity, and her skill at Signing. Arthur's easy intelligence, lipreading skill, and charming manner also helped to break the ice. However, both knew how easy it was to cause offence when the wrong thing was said or done. Gwen related:

> "...we know a couple much older than us who are in (the) Break Through (Trust)...(Sheila's) partially hearing...(and Jack's) a teacher of the Deaf...If there is a problem,..(Jack's) there ironing it out,..(for example), we had a 'skittles' evening and there was a problem over money for the coffee, so (Jack) paid for it himself...and said, 'Oh well, we don't want to give Deaf people a bad name'."

Arthur and Gwen believed that Jack's apparent kindness was actually motivated by a fear that his image and that of his companions would be tarnished by the stereotype of Deaf people being childish and irresponsible.

However, Gwen went further than Sarah or Jack in understanding that what their deaf partners really wanted were friendships based upon equality, whether with themselves or other hearing people.[41] Because of the very nature of the disability, this is difficult to achieve unless the adjustments necessary are seen in a new light. This aspect of the problem will be discussed in the next section.

REVISIONING THE ADJUSTMENTS REQUIRED BY HEARING PEOPLE: LOOKING AND REPEATING

If people with acquired hearing loss are to be perceived as 'different' and 'equal', a revisioning[42] process has to take place. It has already begun in the Deaf community as linguists have given Sign language a new respectability, proclaiming it to be a genuine language with its own syntax.[43]

Although people with acquired hearing loss do not require those who hear to learn a new language, they do require cooperation so that lipreading can take place. This cooperation is about making themselves truly accessible to relaxed communication with people with acquired hearing loss. While there are many factors that could be explored here, certain key factors have emerged in this study as being the most helpful in the communication exchange.

As we have seen, hearing impaired people need ETTA (the Effort Time Thought and Attention) required so that a relaxed conversation can begin. For a conversation to continue and a relationship developed, two other important interactive processes have emerged: 'looking' and 'repeating'. For relaxed communication to flourish, these two processes need to be seen in a fresh light.

Sociologists,[44] social psychologists[45] and linguists[46] suggest that 'looking' or gaze behaviour facilitates the development of intimate relationships generally. There is clear evidence for a looking-liking connection of the following type:

> "the more you look at me (the more attention you give me), the more I will like you."

This connection is confirmed in Ellyson's study which shows a correlation between 'looking' behaviour and husbands who are well adjusted in their marriages.[47] Ellyson observes that these husbands both looked and listened to their wives when their wives spoke to them. The 'looking' behaviour is seen to be a reflection of the husbands' desire to understand rather than control their wives. This finding implies that the

'looking behaviour' required as a communication strategy for people with acquired hearing loss, does in fact facilitate intimate relationships more generally.

In a similar way, 'repetition' has been discovered to be of greater value than conventionally understood.[48] Tannen argues that 'repetition' is a pervasive, fundamental infinitely useful conversational strategy; it has varied purposes for example production, comprehension, connection and interaction.[49] In addition, it gives poetry its rhythmical character and has in fact been highly valued and studied in literary texts. Gertrude Stein said:

> "Repeating then is in every one, in every one in their being and their feeling and their way of realising everything..."[50]

Resistance would be expected to requests for behaviour change along with the above interpretation of 'looking' and 'repeating' and the conceptionalisation of ETTA.[51] There is also a cultural dimension in that English people have not been known for putting their energy into intimate, emotional and personal communication.[52] However, for hearing impaired people themselves and their hope for friendships built upon equality and reciprocity, these conceptualisations suggest a way of transforming the perceived caring obligatory aspect of communication with them into something of greater value and interest.

Since this chapter has touched on the attitudes of professionals, it is appropriate to explore the situation in more depth.

PROFESSIONALS AND SERVICE PROVIDERS: HOW HELPFUL?

The discussion now focuses on Unger and Powell's second level of support for families where there is a disability. This level contains neighbours, more distant friends and relatives and selected professionals and service providers. Research suggests that families where there is a disabled member tend to use medical and other formal support services as much as other families, but they tend not to utilise them to a degree consistent with their level of need.[53]

In looking at the specific professional - client relationship, Appleton and Minchom describe the professional-client models which are used when working with children and their families.[54] Here they have been adapted for professionals working with clients who are disabled. They are called the 'expert model', the 'consumer rights model', the 'social network/systems model', and the 'empowerment model'. As the latter will be the most relevant in the 1990's, it will be described. The 'empowerment' model has three main tenets. Firstly, professionals actively promote their clients' sense of control over decisions affecting them. Secondly, they are sensitive to the rights of clients to opt into the professional system at a level they choose; and lastly, professionals must be sensitive to the unique adaptational style that each family and social network employs. These three tenets are not a blueprint since each family is unique. However, their focus on service quality and consumer control is representative of the empowerment approach which is now believed to be crucial in the long term for promoting emotional growth and a responsible attitude in both clients and professionals.

The evidence of this present study was that there was a wide range of professional help available to people. It varied not only in its specific nature, but also in it's effectiveness. Some excellent sensitive help was offered alongside help which was felt to be ineffective and unsatisfactory. There were also examples of attempted help which was destructive.

DOCTORS

Contrary to expectation, people who received the worst treatment from doctors, did not necessarily feel the most anger towards them. Two profoundly deaf men perceived that they had actually been deafened by drugs prescribed for them by doctors. However, neither appeared to be harbouring great bitterness because of it. Sam remembered:

> "...About four months before I became deaf, I had an infection in my ear. I went to the doctor to see about it and I had an injection to clear up the

infection...the infection cleared up. After that I started to experience giddy spells with the room going round and round and then quite suddenly I became deaf in the left ear. Then gradually over a period of time,..I became deaf in the right ear...When I became deaf in the left ear which was very sudden, I went back to the doctor (who) had a quick look in my ear and sent me straight to the Ear Nose and Throat Hospital to see the specialist and they said they might be able to do something..."

At first Sam and his mother like many others, were hopeful for a cure.[55] However, after further tests, Sam recalled he was told :

"...there's nothing we can do about it; sorry about all that', but I think the cause was drug toxicity (from the injection I received for the infection). I can't prove anything now."

This first experience along with subsequent experiences since had left Sam feeling:

"Well, I don't think I've had much help from doctors in the medical profession...the impression I get from them is that if they cannot do anything,..they are not interested. They'd rather deal with people they can have more success with..."

Sam's partner, Julia, spoke more forcefully against the doctor who had treated Sam expressing her belief that it was only Sam's amazing fortitude which had carried him through the experience so well. Nigerian Anthony, had a similar initial experience; but eventually, perhaps partly because he was a doctor himself, he had received excellent care at the hands of the medical profession in that grants were found for his complete rehabilitation.

The people in the study also mentioned difficulties with doctors concerning the diagnosis of deafness. In one case there was a misdiagnosis. Martha related:

"No, I blame the doctor that attended me (then). I was seven or eight...it was during the war (when) I had scarlet fever...which was very rare...and the doctor thought it was tonsillitis."

Regardless of the misdiagnosis, it may be that the outcome of her illness at that time in history would have been the same; however, in Martha's eyes, a doctor had made a mistake from which she had suffered. There were other people in the study who recalled their doctor's insensitivity at the time of diagnosis. Deafened Joy remembered how her doctor presented her with a piece of paper on which he had written her irreversible condition, at a time when she was unsupported. Mike, her husband, remembered his own feelings:

"...when Joy was first in hospital...the surgeon told me that there was no possibility of...(her hearing) ever coming back again...At that particular time, it did really upset me..."

Mike and Joy had a mixed experience with their medical care. Many years later Joy was pleased with the quality of care she received during and after her cochlear implant operation. Barbara also had a mixed experience. Currently, she was pleased with her GP who was open and direct and did not patronise. Previously, she had been less fortunate in seeing an ENT consultant who had doubted her word when she told him her degree of deafness until he was presented with her audiogram, at which time he apologised.

Joe and Anne had more satisfactory experiences with their medical care. Anne found her ENT consultant helpful when she was working out whether or not she wished to wear a hearing aid as she felt that he treated her as an adult capable of making wise choices. Joe benefited from his doctor's interest which assisted him in meeting his second wife.

Perhaps a better way of exploring the quality of the relationship between hearing impaired people and the medical profession is through an analysis of their experiences with regard to acquiring hearing aids. With reference to Unger and Powell's model,

this process of hearing aid acquisition takes place on the third level of more distant professional relationships specifically those based in social/medical institutions.[56] We will now explore this process as a social policy issue.

THE PROCESS OF HEARING AID DISTRIBUTION: A SOCIAL POLICY ISSUE?

People's feelings about their hearing aids are complex.[57] Undoubtedly there is some connection with how people feel about them and how they are actually treated when fitted with one. Although patients may see their ENT consultant or his resident on special request, they usually encounter hearing aid technicians who service and distribute the aids and batteries. They perform a very useful service, but additional information is difficult to obtain. The professor in this study made an attempt to find out some basic information about his acquired hearing loss. He was met with the following reply by the technician.

> "Oh you'll have to get a letter from your doctor, we can't tell you this...that's the way we do things."

This reply irritated and angered Frank who was joined by other people in the study in making the point that the patient at the bottom of the NHS bureaucratic structure felt depersonalised when attending the ENT clinic. As it happened, Frank in his capacity as a university administrator, was able to address his complaint to the former Dean of a London medical school who happened to be chairing one of the many meetings which Frank attended. Frank bluntly stated:

> "I think most of the medical men treat their patients as if they are 'morons' you know."

The Dean defended his profession by saying:

" Well different patients react differently. Some really don't want to know the details about what's wrong with them: others want to know with precision when in fact we can't give a precise diagnosis."

The Dean appeared insensitive to the destructive effect caused by the indiscriminate use of the blanket policy of nondisclosure. People wanted to understand their condition and did not feel that ' a label' was sufficient. This suggests that information and rehabilitation counselling would have been more appropriate.[58] Even if they did not want hearing aids, all the people in this study wanted to know the facts about their or their partners' condition and some went to considerable lengths to discover them.

This suggests that the implications for social policy are twofold: doctors as part of their training generally need to learn firstly to assess their patients' resources for coping with 'loss'. As part of this assessment, doctors need to learn to speak the truth as they perceive it gently and directly; and in doing this, they need to trust their patients to mobilise the resources they require to manage what is told to them.

Secondly, although not a straightforward matter,[59] doctors need to develop a deeper understanding of their therapeutic function in relation to their hearing impaired patients.[60] They may do this specifically by being honest with themselves and their patients about their own limitations. This means that they have to trust themselves and their patients to resolve their initial feelings of disappointment in discovering the doctor's fallibility in not having a cure for deafness. In most cases doctors are intelligent, dedicated, and skilled human beings, but they also have diagnostic, therapeutic, professional and personal limitations. If the patients are allowed to see their doctors struggle, it could help them come to terms with their own limitations.

These findings therefore suggest that a more discriminating and enlightened social policy in the manner of distributing hearing aids would be of significant help in transforming the patients' attitudes to their disability, and its specific symbol, the hearing aid. This policy could be implemented by doctors being taught to be more 'open' with their patients, treating them in a more adult manner and being aware of psychosocial issues.

Arthur, the person in the study originating from the Deaf community, believed it was not just doctors who had ill used their influence. The focus now shifts to Arthur's specific views about other professionals.

OTHER PROFESSIONALS: CAN THE LEGACY OF THE PAST BE TRANSFORMED?

Arthur began by explaining his view:

> "...I am always suspicious of the motives of professionals who work with Deaf people, for example two professionals in particular...doctors and teachers...are strongly anti-sign language. For hundreds of years, sign language was not used in Deaf schools. I think the teachers and the doctors were in the forefront in that they could tell the parents that the child should not Sign, that they should only talk, and no waving hands around. They would be fitted with hearing aids so in that way oral communication became more dominant,..(as) parents of Deaf children would only listen to the professionals,...they would not listen to Deaf people because none of them had met Deaf people before..."

Arthur's partner, Gwen, had a slightly different perspective. She thought that misleading Deaf people[61] could be the result of inexperience and that sometimes professionals knew their knowledge or the system were inadequate, but had no idea how to improve it. Arthur and Gwen were unanimous in their belief that social workers were ineffective when interacting with Deaf people. Arthur said:

> "I suppose a lot of these social workers like being with Deaf adults.., but they tend to see Deaf people as being like Deaf children needing help,..at least social workers do far less harm because the harm has been done anyway when the children were small..."

This was because of the social workers' attitudes in that they continued to maintain an HCD (Hearing Construction of Deafness).[62] As we have seen, this is a negative

conception of deafness which contrasts with a more positive conception held by members of the Deaf community or DCD (the Deaf Construction of Deafness). Arthur recalled:

> "I used to go to Deaf clubs...I am not a member any more...it was the way these clubs were...run...to my mind,...(the social workers) see these Deaf clubs as part of their fiefdom."

Arthur's view is supported by much of the evidence in the disability literature.[63] Gwen wished to balance this perspective, but she also alluded to HCD (Hearing Construction of Deafness). She said:

> "...(this situation) is not so much now as in the old days...a lot of professionals seemed to think there is something wrong with the deaf person that has to be put right..."

Although aware of all these injustices, Arthur acknowledged the responsibility of Deaf people in transforming the HCD. He said:

> "I think Deaf people themselves do not help by relying on the social workers for help,..(and) in many ways...social workers sub-consciously encourage (dependency)...(in order) to safeguard their jobs...that's my opinion..."

Arthur's point of the 'needy helper' of Deaf people is well supported in the counselling literature.[64] Corker succeeds in creating a useful typology of needy counsellors, of these, 'the benevolent humanitarian' is the one that exemplifies Arthur's specific point.

Gwen appeared concerned that Arthur did not mix his rhetoric with reality. She focused on the social worker who currently visited them:

> "Ours is all right,..It's an automatic thing...'deaf'...you get on the books of the social worker...(it would be) better for those who (really) need it."

Arthur added:

> "The one in this area is very good - he won't see you unless you want to see him."

Neither Gwen nor Arthur understood that having a social worker today is a completely voluntary matter. Because most local authorities are understaffed, Gwen was correct in assuming that the need was greater elsewhere. It would appear that their social worker or deafness worker had adopted the model of 'information/link' which Parrott suggests may be the model of the future.[65]

Throughout this discussion, Arthur refused to claim a definite cultural identity for himself as other members of the Deaf community have done.[66] Like others, he focused on the acceptance of BSL as the way forward to accepting Deaf people as "the act of Signing itself has become a declaration of political affiliation".

Although members of the Deaf community may now be operating with these criteria, the situation is far more complex than Arthur presented. There are many people who might like to learn BSL for one reason or other, but find it too difficult, as for example Arthur's own parents' in-law, Beatrice and Andrew. Conversely, severely hearing impaired Henry (40), talked about his feeling of liberation when he first began Signing classes:

> "I felt I was in a straight jacket before I learned BSL...at first I was terrified of using it...The tutor (called it taking) 'a sacred vow with which to overcome your inhibition'. In other words, it doesn't matter what people think...(as long as it's) 'ok' for yourself."

While Henry obviously benefited from BSL, in that it helped him to adopt a more positive identity or Deaf Construction of Deafness (DCD),[67] it was less useful for other members in this study. Despite the fact that they had the same degree of hearing loss as Henry and Arthur, their identification with the hearing world was stronger, and they had made a certain peace with the communication strategies already available to them.

One group of professionals which Arthur did not condemn for their misuse of authority was the clergy. Religion, implicitly if not explicitly was an important aspect of Arthur and Gwen's life and for this reason, they chose a church wedding. A chaplain of the Deaf married them and the service itself was done in English and BSL. The next section will focus on what other people in the study felt about the support which their faith, or involvement with a community church gave them.

RELIGIOUS INVOLVEMENT

Research suggests that church membership, like some other associational groups, allows the suspension or realignment of the expectations of reciprocity and mutual exchange on which friendship and neighbouring usually depend.[68] This may be one of the reasons why historically church membership has been particularly important for prelingually Deaf people.[69]

In continuing with the third level of social support,[70] the people in this study represented a wide range of feelings and experiences with regard to their personal faith and more formal commitment to church attendance, worship and fellowship. Although the practices of the people here can not be generalised to the total population because of the small numbers involved, some interesting evidence emerged. For example, as many as nine of the 27 people studied here were regular attenders of a church or synagogue, six were occasional attenders, five were episodic and seven were what might be called visitors. Despite the fact that it was difficult to hear in many churches since loop systems had yet to be installed, although this is slowly improving, the people in the study still went and regular attendance was actually 17% higher than found in the population at large.[71] Four factors which may be important in explaining this are tradition, fellowship versus solitude, loop systems and belonging, and the clergyman as support.

TRADITION

A number of people in the study based their decision to be involved with a church on the tradition of their families that is 'the living faith of those who have died'.[72] Arthur and Gwen, from strict Church of Scotland backgrounds, talked about their decision to be married in church rather than to cohabit or be married in a register office. Arthur explained:

> "I think it was sort of a deeper instinct...partly religious tradition...That sort of thing...(is taken) very seriously in Scotland. If for example, people lived together on the Isle of Lewis in the Hebrides (where Gwen's family come from), they'd be shunned."

Gwen agreed:

> "It's conditioning...family and other sorts of ties...religious partly, cultural...well I don't come from an environment where people live together..."

Arthur and Gwen were only too aware of the stigma which accompanied deafness. Because of their close family ties, they did not wish to risk causing offense and further stigmatising themselves by living together before marriage.

FELLOWSHIP VERSUS SOLITUDE

The people in the study varied in how much fellowship they hoped for when attending a place of worship. One hard of hearing woman of 84, Theo, attended an evangelical chapel. She described her experience:

> "...I take my Bible and the person (who) sits next to me...finds the place if I don't hear,..immediately...(I) have a friend (who) looks after me."

While Theo was able to experience the helpfulness of others in church, severely hearing impaired Joe, who regularly attended synagogue, found the greatest

satisfaction from just being at peace rather than in relating to others. In contrast, his Gentile wife, Sarah, enjoyed socialising in the synagogue for it's own sake. Beatrice, Gwen's mother, experienced a deeper kind of social support from her church network.

These examples illustrate the capacity of each individual to find what they needed in church or synagogue experiences. However, some people in the study, experienced deep frustration in connection with church attendance. Severely deaf Henry, aged 40, had particular difficulties. Whereas he and his wife were both studying for the Ministry, Henry suffered greatly whenever he attended the fellowship hour in the church hall after the service. This was because he desperately wanted to relate to others, but felt helpless because the 'background noise' made his hearing aids useless. Kay, his wife, described a row they had after a Sunday service:

> "I thought (after the teapot lid had broken and Henry had been upset) that (he) was just resenting...that I'd been in the limelight (preaching) at church, but he said distraughtly: 'I don't know anybody there...nobody talks to me'."

Kay reflected further:

> " ...Once I realised that...(Henry) was feeling isolated with so many people,..and nobody talking to him...and Clive...(our son) misbehaving,...and also the business about our (uncertain) future...and just general tiredness which Henry's been feeling,..a combination of things,..(then) the tension disappeared and we were able to calm down and...meet. But sometimes there are just sort of misunderstandings."

With not even his wife truly supporting him, it was understandable that Henry should feel isolated and helpless, unable to get out from underneath his inspirational image, and unable to clarify his needs in an adult way.[73]

This illustration points to the domino affect which could result when there is no strategy for helping a severely hearing impaired parishioner integrate into the church's fellowship hour. In this particular case, lines of responsibility for this process were

unclear. Once Kay understood how Henry was feeling, it was their joint responsibility to explain the problem to her vicar or someone on the staff of the theological college which Henry attended so that helpful strategies could be formulated. Although those in authority might be unfamiliar with the specific needs of hearing impaired people, they could listen.

In the second instance, as Henry became more confident, he needed to be more open about his need for clarification, and for taking time off when he got tired and felt stressed.

The final step is for the implementation of a mutually formulated integration strategy. This subject cannot be dealt with adequately here, although it is possible to make a start. For example, on days when Kay was to preach, someone could volunteer to help Henry with the children thus freeing him to concentrate on lipreading parishioners. He could be encouraged to meet members of the congregation in their homes where the atmosphere is usually more relaxed and he would be able to use his hearing aids. This would mean when Henry did meet people in the more formal setting of the church hall, he could build upon a relationship that had already begun rather than meeting a complete stranger with unknown lip patterns.

THE INDUCTIVE LOOP SYSTEM AND BELONGING

The inductive loop system is the most common device installed in churches to aid hearing impaired people. A 'magnetic field' is produced by running a circuit of wire around a room which plugs into an amplifier, part of the sound system. The sound is received by the hearing impaired person with no background noise provided they have a 'pick up coil' in their hearing aids which most aids now have. The effect is threefold: the sound comes directly from the microphone into the ear rather than from some far off loudspeaker making the sound clearer and less distorted, volume can be individually adjusted, and all background noises from sources outside the loop are eliminated.[74]

All churches do not have loop systems which work adequately if they manage to have one at all. Max, an elderly widower, was not one of the fortunate ones. Although he had lived a full and rich life as a husband, father, teacher, headmaster and once President of the National Union of Teachers, he now found himself unable to hear in his local church. He said:

> "... I used to go up to this church, All Saints,...but I don't go now...not because I haven't any difference of (religious) view,.. but I can't sit in that church and...hear a good sermon!..I know that's not the only thing you go to church for, but I can't hear a single sentence,..it's a lovely church...and I like to go,..but it doesn't seem worthwhile."

Max's example was representative of the problems caused when elderly intelligent people are cut off prematurely from the stimulating aspect of faith because they cannot hear the preaching. The question must then be asked, "Who is it who speaks up for hearing impaired people and their needs in the local churches"? Although various groups have begun to campaign for the rights of hearing impaired people (for example, the Hard of Hearing Christian Fellowship), the established Church of England has barely begun to address this problem. This was evidenced by the fact that in the 150 page report entitled drawn up by the Church of England's Social Policy Committee of the Board for Social Responsibility, there was no mention of hearing impairment.[75]

THE CLERGYMAN AND HIS CHURCH AS SUPPORT

A theme that ran through people's comments on church involvement was its importance in times of trouble, special occasions, and status transitions. Deafened Sam and his partner, Julia, talked about their experience. Julia said:

> " I go some times...only...(Sam)...(doesn't) come with me. It's boring...(he) can't hear anything. I like songs at Christmas time...I like to go to the Carol services."

Although Julia can hear perfectly, it was really only the Christmas music which drew her to church. She also admitted that if she was ever in trouble, she would be the first to turn up in a church. Sam saw it slightly differently:

> " It's alright...I like singing hymns and carols.... But if I'm at a service and there is a hymn, I have to look at other people to see if I'm keeping up with them...or if I'm singing the right words in the right place..."

Sam had accepted the situation although he had sung in the church choir as a boy making church attendance part of his childhood upbringing. He explained his religious feeling:

> "Yes,..I believe in God, but I don't think he is continually working over everybody directing people's lives...he let's you get on with it...he's with you, but as a friend..."

Sam was not alone in seeing God as a friend. Anthony's wife Clare, also had a strong supportive sense of God. She said:

> "Getting close to God...gives (me) immense help and strength to cope with the problems (caused by having a deafened partner). There are times when all ... (I have) to rely on is...(my) faith,...and that alone is enough to see...me through many hard times."

Besides help coming from a person's faith, it also came from relationships formed with specific clergymen. Christine mentioned how her minister supported her through the loss of her hearing, her divorce, and the eventual death of her husband.

> "...my (Methodist) pastor...(said to me)...why don't you stop fighting with the evidence, (that I was losing my hearing), and start using it? So I went... back to school and became a rehabilitation counsellor for Deaf people and learned Sign ..."

In hindsight, Christine looked upon this time as a major mid-life crisis. Because of the support she received from her pastor and a rehabilitation counsellor, she was able to retrain and gradually moved into a career where she could use the experiences which had happened to her.

Lastly, Gwen recounted the importance of having a chaplain of the Deaf officiate at her marriage to Arthur.

> "(Arthur and I) both Signed through the wedding. The chaplain ...Signed, and we employ(ed) a professional interpreter who ...interpreted all the service,..and the chaplain did the hymns...I had to learn (new) Signs as...I didn't know the Sign for 'Holy'..."

The place of the chaplain of the Deaf, who in this case stepped in for Gwen's recently deceased minister, was crucial. He conveyed that Arthur and Gwen were not only making a commitment to each other, but also to the rights of Deaf people.[76]

In reviewing this section on church involvement, there is a huge gap between what could be done for hearing impaired people and what is being done. Loop systems are a start, but many people are still missing out on what could be a more satisfying experience of worship.

SUMMARY

This chapter has looked at the impact of hearing impairment on friendships, upon relationships with professionals, and upon religious involvement.

It emerged that the friendships of hearing impaired people could be immensely improved if revisioning took place towards the two primary adjustment processes required by hearing people to enable lipreading: 'looking' and 'repeating'. For example, Noller points out that 'looking' is a positive interactive strategy in intimate relationships and helps to facilitate them regardless of hearing ability.[77]

In a similar vein, Stein[78] and Tannen[79] point to the immense value of 'repeating' both in Literature and as a basic human process. The revisioning of these two concepts could help to transform the caring obligatory aspect of communication with hearing impaired people to something of greater value and interest.

However, before looking and repeating can be processed, the ETTA factor must be acknowledged. It is about giving hearing impaired people access to general conversation in public as well as private places, to information, as well as to intimacy in specific friendships, in a similar way as providing a ramp for a wheel chair gives access to people with problems in mobility.

In the discussion of old and new friendships, it is clear that friendships do not necessarily diminish when one becomes hearing impaired. Much may depend on what social skills the person had before becoming deaf, and their proximity to old friends. Indeed friendship are and could be formed on the basis of reciprocity and equality. This was acceptable as long as it was understood there would be an instrumental aspect of the friendship from the beginning. It also emerged that two deafened people, Joy and Sam, found helpful understanding in cross gender relationships.

Overall hearing wives were more worried about their deaf husband's social network than the men themselves. These wives appeared ignorant of how men develop friendships. There was a suggestion that a feminine style network might be appropriate for a man especially during a time of 'adjustment'.

The analysis of hearing impaired people's relationships with professionals was seen in the context of social network formation where there is a disability, using Unger and Powell's three levels of intimacy.[80]

It is recognised that the prelingually Deaf, as represented by Arthur in this study, and well supported in the literature, have a long history of grievances with professionals especially with doctors, teachers and social workers whom they feel are responsible for instilling feelings of inferiority in many prelingually Deaf people. Clergyman, on the other hand, have managed to retain a helpful image.

Discussion concerning how doctors could better help their hearing impaired patients to accept their hearing aids indicate the benefit of doctors being more human and open in talking to their patients about hearing loss. Just because doctors cannot operate, does not mean that they have nothing to offer.[81]

From examining the impact of hearing impairment on social networks, the study moves to looking at its impact, specifically on elderly people when a hearing partner has died leaving the hearing impaired partner to cope on their own.

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[70]Schilling, Gilchrist and Schinke (1984) p. 49.

[71]Brieley, P. (1991) Christian England (London: MARC Europe) p. 30.

[72] Pelikan, J. (1971) The Christian Tradition, A History of the Development of Doctrine . The Emergence of the Catholic Tradition (100-600) (Chicago: University of Chicago Press) p. 9.

[73]See van Dongen-Garrad, J. (1983) Invisible Barriers: Pastoral Care with the Physically Disabled (SPCK:London) p.29.

[74]Webb, H.W. (1989) 'The Pastor's Opportunities XXVI: Ministry to the Hearing Impaired' The Expository Times ,**100**, pp.328-332,

[75]Ageing (1990) A Report from the Board of Social Responsibility (London: Church House Publishing).

[76]Harris (1995) pp. 157-162.

[77]Noller (1984) p. 172.

[78]Stein (1935) p.213.

[79]Tannen (1989) pp. 36-97.

[80]Schilling, Gilchrist and Schinke (1984) p. 49.

[81] Looking at the role of professionals in the lives of hearing impaired people will be completed in Chapter XIII where there will be a discussion of the role of hearing therapists and professionals who are not formal rehabilitators. The importance of social networks in the lives of the study participants can also be seen in the charts found in Chapter XIV.

CHAPTER XII THE PERCEPTION OF THE IMPACT OF HEARING IMPAIRMENT ON THE SURVIVING PARTNER DURING AND AFTER BEREAVEMENT

INTRODUCTION

The previous chapter investigated how hearing impairment affects the social network focusing on friendships, professionals and church involvement. This chapter examines the consequences of the ending of a marital relationship through the death of one partner when the bereaved partner also has an acquired hearing loss. Interesting though the experiences of younger people are, in practice, they form only a small proportion of the hearing impaired population. For example at least three quarters of the 7.5 million adults with hearing loss in the UK are over 60 years old. In the 61-70 year age group, at least a third have some degree of hearing loss and at least 10% have a loss which is moderate or worse. In the 71-80 year age group, over half have some degree of hearing loss and at least 20% have a loss which is moderate or worse.[1] Consequently an ever growing older population means that hearing impairment will become an increasingly common, sweeping, and insidious condition in society, resulting in its developing significance and need for recognition as a social problem.

In this chapter a comparative case study approach is used to examine the adjustment of a widower, Max, and a widow, Theo. The interviews took place after they had both lost their respective spouses and had acquired a hearing loss. There were other losses present such as the loss of status which results from being elderly and retired, but this was seen as more peripheral to this analysis. Whereas widowhood has received a certain amount of scholarly attention,[2] with a few exceptions,[3] the lives of widowers have been neglected. Another reason for focusing on a widower is that recent findings suggest that men are closing the gap with women and dying later than in the past.[4] In this study, 'access' was given by Max's two daughters and their families which made it possible to obtain a particularly rich profile of him in his roles as father and grandfather. This makes for a certain imbalance in this chapter as the widow, Theo, could not offer her family for the study because her only son and

his family lived in the USA. However, an examination will be made of how she created an adopted family and had a highly developed social network.

The salient factors which made it possible for Max and Theo to integrate their losses so that a new equilibrium could be established will be analysed. Questions raised with reference to 'adjustment' were about such factors as proximity of kin, proximity of friends, personality and relational skills, past career experiences, the quality of the previous marital relationship, the maintenance of personal control, the proximity of 'community care' programmes,[5] lipreading classes[6] and 'self help' groups for the hearing impaired,[7] specifically for elderly hearing impaired people who live alone.[8]

There will also be a short exploration of the psychosocial unconscious healing processes used by Max and Theo which enabled them to come to terms with the double loss of their respective spouses and normal hearing. Lastly, it is argued that the basically positive accounts which follow are necessary to balance the largely negative literature on elderly hearing impaired people.[9]

MARITAL BREAKDOWN

The literature suggests that a satisfactory marriage provides protection against physical and mental ill-health because it acts as a buffer against the effects of anxiety and stress.[10] However, a gender imbalance emerges in marital research suggesting that such benefits for men far outweigh those for women.[11] Consequently, when these strong emotional ties between adults are broken, the severance is often accompanied by anger, anxiety, and depression, exacerbated if the break is unexpected or undesired.[12] The Holmes and Rahe's Social Readjustment Scale, which measures life events through life change units, puts the death of a spouse at the top of its list while divorce and marital separation are also very high on the scale.[13]

Thus marital breakdown, regardless of its exact cause, usually generates enormous amounts of stress over a long period of time. The family therapy and sociological literature explores how the family system responds to the death of a loved one.[14] Besides the impact on the welfare of the family as a whole, marital breakdown has an effect on the physical and emotional health of the individual adults[15] and children.[16] Married people of both genders have been found to be emotionally and physically healthier than people who are not.[17]

MARITAL BREAKDOWN AS EXPERIENCED IN BEREAVEMENT THROUGH THE DEATH OF A PARTNER

The literature portrays the finality of death as closing off relationship options, making it an emotionally overwhelming crisis for most families. Although the death of any family member carries with it a sense of grief, the death of an elderly person who has lived a full life does not usually arouse the degree of anger often associated with untimely death, nor does it carry the potential for major gender role changes as it does when it occurs with young or middle-aged family members.

Sudden death of a significant family member throws the family into severe shock and sometimes 'emotional shock waves' occur. This network of 'after shocks' can occur anywhere in the family system in the months and years after the death.[18] Eventually the shock wears off and the bereavement process begins. The family is forced in due course to come to grips with stages of grief. Grief here is defined as the psychological process of adjustment to loss and involves feelings of numbness, pining and depression.[19] In most cases recovery is achieved and there is a reorganisation of the family system and a reinvestment in other relationships and life pursuits.[20]

Psychologically individuals experience grief as an expression of a profound conflict between contradictory impulses. On the one hand, one needs to consolidate all that is still valuable and important in the past, and preserve it from further loss; and on

the other, it is important to re - establish a satisfying pattern of relationships in the present where the loss is understood and accepted.[21]

DETERMINANTS OF THE OUTCOME OF BEREAVEMENT

The literature suggests that adjustment to the loss of a partner is initially worse for women, but more difficult for men in the long term. Husbands traditionally occupy a larger part of the life-space of their wives than the wives do of their husbands. For example, the wife's roles, plans and problems tend to be husband-centred and she may be reliant upon him for money, status, and company to a greater extent than he is on her. However, the literature also suggests that while overt manifestations of grief are more pronounced in women than in men, it is the women who are the first to recover from bereavement in the long term.[22] In fact there is evidence that widowhood can be a liberating transition for women after which a flowering of new activity may follow involving new periods of parenting and step-parenting.[23] For men, also, new parenting experiences remain a possibility until the end of their lives.

The literature suggests that while gender is undoubtedly a highly significant factor in determining the outcome of bereavement, other factors need to be considered. Briefly they may be divided into four categories: a) background experiences of loss; b) relationship with the deceased prior to death; c) concurrent social factors of the bereaved partner for example, sex, age, personality, socio-economic status, religion, nationality, and d) subsequent support, secondary stresses and life opportunities experienced after the partner's death.[24]

The discussion will now shift to examine the lives of Max and Theo in more detail.

A COMPARATIVE CASE STUDY OF BEREAVEMENT: A WIDOWER AND A WIDOW

Because the elderly and disabled identity of Max and Theo was acquired over time, biographical details are of central importance in understanding their experiences.[25]

MAX: DESCRIPTION AND BACKGROUND

Max was a tall athletic looking man who carried his 81 years with dignity. He had lived alone since his wife, Dora, had died seven and a half years earlier. He had been a teacher, headmaster of a secondary school in Croydon, secretary of the borough's Teaching Association, and eventually president of the National Union of Teachers for one year. As we encountered in Chapter XI, Max had two adult daughters, a teacher and a social worker. The younger, Margaret and her family, lived in a house further up the hill in the street where Max lived; while the elder, Esther, lived further away, but in the same locality. This arrangement had made it easier for Dora to care for her grandchildren when their daughters went back to work. However, both daughters recalled that they had seen very little of their father while their mother was alive, as he was so involved in his teaching activities, a situation which they did not wish to repeat with their own children.

Thus almost by default, Max now in retirement, found himself able to keep in regular contact with his five grandchildren from the ages of 11 to 25. From his daughters' perspective, living close by made it easier to keep an eye on their father's welfare although this was often a difficult task due to ambivalence on both sides.[26]

THEO: DESCRIPTION AND BACKGROUND

Theo was a petite slightly stooped white haired woman of 84. Behind a personable manner appeared to lurk shrewdness balanced by an enormous sense of fun. Like Max, Theo had formerly been a teacher. For the last seven years, she had been the

head mistress of a primary school. Unlike Max who retired at 65, Theo was able to carry on until 71 because she worked in the private sector.

Theo felt that it had taken her three years to come to terms with her husband, Will's, death which had occurred four years prior to the interviews. He was ten years older than her and had been a pharmacist and an optician. They had one son, Philip, who was currently in the Head Office of a major oil company in Washington DC. Until four years ago, he, his wife and three children had lived nearby, so it was a double loss for them to leave the country just prior to his father's death. Although Theo's natural family no longer resided in England, she had many familial relationships,[27] a strong faith, and rarely felt alone.

THEO AND MAX REMEMBER THEIR PARTNERS

Max introduced discussions of his beloved wife, Dora, by saying how very beautiful she was, illustrating this by showing two photographs, one of her as a young girl, and one taken just before she died. His manner of doing this was like a ritual, an apparent effort to seek a sense of partial closure.[28]

Max recalled:

> "...so I don't know how I (managed everything)...if I hadn't had the wife I...(had), I couldn't have done it... because I was ...(rarely) at home some evenings,..she was always here when I came back, looking after my daughters,..the grandchildren, and also... me..."

Max acknowledged his good fortune in having married such a devoted and nurturing woman, although Dora may have sacrificed something of herself so that both her husband and daughters could be high achievers.[29] He gave a moving account of the day Dora had died:

"She had a heart attack and was in hospital for a short time. She had come home and appeared to recover somewhat. It had been a beautiful summer's day. I suddenly realised about a half an hour before she died that she was dying. After it occurred, I went to my Roman Catholic neighbour and asked her to say a prayer even though I'm not a religious man. I felt a light had gone out of my life."

While Dora died relatively unexpectedly,[30] Theo recalled that Will's condition gradually deteriorated and it was necessary for them to move house and buy a bungalow which was accessible to Will's wheel chair:

" (Will)...used to go...in...(his) wheel chair...(on) a ramp,.. (so that) he could go right up to the edge of the patio...In the spring there are daffodils...all the way around...(the house) it was nice to think that he was happy...(here)."

Will's eventual death at 89 appeared to leave his family free from any lingering guilt or grief and they could get on with their lives. Max, on the other hand, took longer to come to grips with his wife's death, perhaps partly because it was so unexpected.[31] Another partial explanation emerged in a discussion of friends. Max reflected:

"Well, the friend I had for life, I lost. Yes, that was my wife...I don't think...I have a mate (or colleague) outside the family (now). I've had them in the past, but with the passing of the years, I haven't got them."

Max, like most men of his generation, undoubtedly cultivated context bound relationships which emphasised sociability.[32] He also appeared to satisfy what needs he had for intimacy by relating to his wife and occasionally his family.[33] Because seven years had passed since Dora's death, it was a little surprising that Max had not cultivated more 'special relationships' outside his family where he could get

back in touch with 'lost' aspects of himself, for example, young teachers with political interests.

Theo also cherished memories of her husband, Will, but they were of a different order from Max's as her marriage had contained some major disappointments and less emotional closeness. Thus Theo did not feel towards Will the same overflowing gratitude which dominated Max's account of his relationship with Dora. Theo speculated on the causes of their problems:

> "(Will) was in World War I...the strain on a young man as he was then, from 18 years to 22 years, in the trenches must...have made a difference to his outlook, to his personality and he said he was afraid, and I had always to cope with that...He had the Military Cross and Bar in the war...so he was very good, but it left him (very nervous)...for no reason at all..."

Theo saw Will's lack of sexual desire for her as directly connected with his war experiences which is likely to be partially true.[34] They did manage to consummate their marriage while on holiday 14 years after they were married. She recalled:

> "...I was very patient...you didn't think of skipping off because you were disappointed,..we went to Devonshire for a holiday (and conceived our son, Philip)...The problem with Will wasn't so obvious after having a child. I suppose in a way, (becoming a father) put him right..."

Despite these regrets, Theo had pleasant memories of Will. She was particularly proud of his fine mind and speech which she could hear long after she had acquired her hearing loss, as well as his achievements in founding a nursing home for pharmacists. She recalled one favourite memory twice:

> "...my husband...was (ill) in bed,.. and I remember (going) into the bedroom very quietly (when) I (thought) he was asleep,..and he suddenly said something to me,..and I said, 'Oh, I'm sorry, I hoped...you wouldn't

hear',..and he said, 'No I couldn't hear you, but I could sense your spirit in the room'...I thought that was so sweet...it was nice..."

Thus she and Will had been able to transcend the disappointments in their marriage, leaving a deep affection at the time of Will's death. Referring to their earlier difficulties she said:

"I'm glad that (I) did have patience, because it was worth it, and I think today some people don't wait to see if somebody's worth it."

Perhaps Theo's optimistic nature and faith were one reason why she was able to have the necessary patience. Max appeared to have more difficulty with his own company, a gender factor suggested in the literature,[35] which will be discussed in the next section.

BEING THERE FOR BEREAVED PARENTS: A SPECIAL SON AND DAUGHTER

Max recalled how his younger daughter supported him:

"... my daughter...pops in most evenings, if only for a few minutes... she realises it's a lonely life, especially when it gets dark at half past four, and you've got to wait until ten o'clock before you go to bed..."

Margaret understood her father's need for companionship. Her ability to be a confidante provided a buffer against some of the negative effects of retirement and being a widower.[36] She reflected:

"...sometimes I don't feel like going,..to some extent it's a duty, but I do also enjoy his company...Since my mother died, I think I'm closer to him than I've ever been in my life..."

While both daughters did feel genuine compassion[37] for their father, they were uncertain about how much care was appropriate. While it was not possible to talk with Theo's son, Philip, his involvement with his mother was revealed in some of her stories. She recalled:

> "Philip had to go (to the USA) on the 2nd of March and Will died on the 18th...it was a difficult time for me...Philip... had only just taken up his new position,..he came back straight away... and stayed a week...made all the arrangements and helped me..."

Philip was there for his mother despite the demands of his new job. Theo was especially moved by Philip's helpfulness in rearranging her sleeping area. She remembered:

> "Philip was so sensible...he moved my bed into the main guest room, and (gave me his father') saying ' You will like this...a firm bed not so soft as your old one...we'll put your bed into the other room' which we did, and so I...have...that nice firm bed that belonged to (Will) ever since."

Philip's action in moving his father's bed into his mother's room, besides being a practical gesture, could also be interpreted as a symbolic gesture by which authority as head of the family was transferred to his mother. It also helped Theo to identify with her husband and thus to integrate his loss.[38]

Although Philip was with his mother during times of transition,[39] what was missing in her life was the more traditional day to day 'tending' family care which took place in Max's family to a certain extent.[40] While Max was most appreciative of the care he received, for example, his daughters' provision of a daily evening meal, this scenario also had its frustrations in that he often felt a burden.[41]

The discussion will now shift to examine Max and Theo's social network.

MAX AND THEO'S SOCIAL NETWORK: FAMILY AND FRIENDS

While many of Max's affective needs were met by his daughters' families, his lack of peer contacts appeared to result in his feeling a low sense of psychosocial well-being.[42] Hearing losses in the elderly people may make them feel they lack credibility as friends,[43] as the communication difficulties caused by the loss can take away the feeling of 'equality' that is such a basic concept of most friendships.[44]

Max appeared to partly compensate for this by attending the Selsdon Hard of Hearing Group. Margaret recalled:

> "...(my father) was very lonely when my mother first died,..and that (is maybe) what prompted him to go...I (didn't think he would like it). He's not that sort of person really...He goes along every Friday afternoon and he really enjoys it..."

Attendance at self-help groups has long been a coping device for people with a disability.[45] Max obviously understood the value of group support, perhaps because of his long involvement with the teachers' union. He explained:

> " ...(the Selsdon Hard of Hearing Group) is a little get-together and I like it, perhaps because I'm meeting people with my own affliction, we have...a disability in common...it's purely social...nothing remedial,...and I like the people there,..and I go to support them."

People with disabilities are often helped to find the strength to 'accept' their disability through social acceptance and approval by other disabled people.[46] Generally, perceived similarity is associated with liking. There is also the suggestion in Max's account that 'shared stress' leads to enhanced cohesion.[47]

While Max enjoyed the atmosphere of the group as a whole, Theo, a co-member and friend, had a special relationship with it's coordinator, Edith. She saw to it that

Theo had all the assistive hearing devices she needed, and generally ensured that she did not get too isolated, for example by inviting her to church services with refreshments at her house afterwards. On the other hand, if very occasionally illness threatened, it was Theo's neighbour, Edie, who did errands for her such as fetching medicine from the pharmacy.

While Theo relied on her neighbour,[48] Max relied on his daughter. Margaret recalled how she 'interpreted' for her father at the surgery:

> "...If (my father sees) Dr Benson,..(who) speaks very quietly,.. (he) can't hear half of what he says,..so usually I go along and act as an interpreter...Because I feel under pressure,..I'm working full time,..I want to make sure that I get him well. I'm not always confident that he will give the doctor the full story,..it's me being in control, that's what it's all about."

Margaret acknowledged her mixed motivations in her treatment of her father.[49] On the other hand, she discriminated and did not accompany him to his pernicious anemia clinic. There were other situations where Max's desire to keep his independence and his daughters' desire to be caring caused some irritating situations. Max's elder daughter, Esther, related such an incident:

> "(Before he went) to London for the evening...I said, 'you're 80 and there're some 'rough toughs' around, and you shouldn't be out on your own at night...I do worry about you. He...(told me when) he was going to be home,..(and then) he didn't come...We (rang) and (rang) to check he'd come in, like a mother with her child really...Finally...he rang...ten past 12 o'clock...(my sister) duly went down to Croydon (in the car) to pick him up. He (told her), 'I've waited 40 minutes for the bus, (but) it didn't come'. She said, 'Why didn't you call when you got off the train?..Oh, I didn't want to trouble you'. he'd said and she replied 'Why didn't you get a taxi if you didn't want to trouble us?' and he replied, 'Oh, I didn't want to spend

the money... 'now that's the sort of person he is...he's annoying trying to be independent..."

Esther's attempt to reverse roles with her father[50] was not effective. While exasperating to his daughters, Max's fight to maintain his control and autonomy was another factor essential to his sense of well being.[51] Thus Theo and Max were forced by fortuitous circumstances to reverse what might be traditionally expected.[52]

While Max found himself surrounded by a protective natural family, Theo found herself in the midst of an adopted family consisting of neighbours, friends, professionals, tutees and a cat. It emerged that this reversal had its advantages and disadvantages. While Max had to fight to keep himself from being over protected, Theo was rarely allowed the physical 'tending' traditionally given to women in their eighties.[53]

Let us now explore how Max and Theo coped with memories of the past and their lives in the present.

MAX AND THEO ON MEMORIES OF PAST SUCCESSES AND REINVESTMENT IN PRESENT COPING STRATEGIES: SOCIAL NETWORK CONTINUED

While Max had found a new equilibrium in his life, he, nevertheless, missed the enormous enjoyment he had experienced in living the active part of his life. He recalled:

"...I enjoyed my life as a teacher. I enjoyed my family life, there were lots of ups and downs you know, feelings of despair, feelings of elation, of triumph and joy, and it's all a lovely old mixture like a currant cake."

Max could not only remember functioning normally, but functioning well under considerable pressure:

"At Easter I go to a conference of the National Union of Teachers. I was President twenty years ago and my hearing was perfect...I mean I was in the chair at a conference of 2,000 delegates...every day for a week, and anybody in the back row who asked a question, I could hear. But if I go to that conference...(today, as)...I'm a trustee and...still eligible to go, I can't hear if I'm behind the microphone."

In the same way that he was able to 'let go' and integrate the loss of his wife, Max was able to mourn and integrate the loss of his career, and accompanying perfect hearing. He managed to do this as demonstrated in his willingness to learn how to cook and clean. At the same time, he maintained a certain minimal involvement in the politics of the teaching profession, in community activities, the neighbourhood, sports' activities, and he kept himself in a relatively healthy state. This had included getting himself one hearing aid from the NHS, and enrolling in a lipreading class.

While Theo also felt diminished by the loss of her husband, job, and hearing, she appeared a little more resilient than Max. She recalled:

"...I enjoyed (my work) so much...I used to write a lot...and the very first article I had (published) was in The Lady, an article called, 'My Lovely Job', because that was how I felt about it..."

Theo acknowledged great good fortune in her job, family, general health and ability to make a rich variety of friends. She explained:

"...I will always have friends anywhere, even say if I were to move to the USA to be nearer my son,..I have no intention of sitting in a corner..."

Although much more confident than Max in her capacity for making new friends, she was equally very appreciative of her very old friends. She remembered:

"...the friend for life in mind,..Margo, I met her when I was teaching,..she was Scottish and very much better-educated than I was,..she was a good friend because she thought I could do anything...About five years ago,..she went blind...and now her greatest pleasure is talking to me on the telephone one, two, three times a week. (It's supportive for me too) because when I finish, I say, 'thank you'."

As we have seen, another member of Theo's network was her hearing impaired younger sister, Jess, with whom she spent Christmas every year. Theo reflected:

"...if anybody is deaf,.. they get...into the way of hearing you the second time...I get a bit tired of saying everything twice,.. in the same sort of voice,..(it seems) in a way (that they) are not attending,..but that's unkind because (Jess) can't help it."

While the two sisters had a different degree of loss, Max and Theo had relatively similar degrees of loss, but heard different frequencies. In other words, Theo heard the birds singing while Max heard the lower piano notes.

It is sometimes argued that hearing loss is less of a problem for elderly people since the statistics suggest it is to be expected.[54] It was, therefore, of specific interest to investigate the response to diagnosis and onset.

THE ONSET OF HEARING LOSS FOR MAX AND THEO

Max first noticed his deafness not long after his wife died. He recalled:

"...I first noticed my hearing was going about six or seven years ago. I lost my wife...in June 1982...my hearing was perfect, but ...perhaps a year after she died, I began to go deaf...and I've often wondered whether the shock of

bereavement,..(her death) was (so) unexpected, was a contributory cause..."

Both daughters had heard a different story. Margaret remembered:

"Well I think we were aware of...(father's deafness) when my mother was alive...because she always used to say 'Oh, he's so deaf!'...I think probably towards the end of her life, she used to get a bit frustrated...(about it)."

Therefore, it was likely that Max's hearing had begun to deteriorate before Dora died. The literature suggests that bereavement is known to trigger the first appearance of chronic conditions in family members resulting from 'emotional shock waves'.[55] The truth may be twofold in that it is possible that Max's deafness began before his wife's death, but was accelerated afterwards. Perhaps Dora had protected Max from the knowledge that he was hearing impaired because she had automatically accommodated to his need for repetition. Moreover, her death exposed him not only to his own deafness, but also to his other dependency needs, such as being unable to cook or clean the house.

Theo was more sophisticated than Max about hearing loss because her mother and sister were hearing impaired. Her gender may also have helped her to face reality more quickly.[56] Theo recalled how she first became aware of her problem at 70 while teaching:

"As soon as I found that I wasn't able to hear the little children,..I remember asking a friend,.. 'I think I'm getting deaf, what should I do? And she said, 'Well I think you should do something about it'. (and) I got a hearing aid."

While onset occurred to Max and Theo in very different ways, the next section reveals their shared sense of loss when confronted with what they could no longer fully enjoy.

MAX AND THEO DESCRIBE FEELINGS OF LOSS AND DIFFERENCE

Max discussed how it was for him on the telephone:

> "...(With) friends,.. I say 'go slower and speak clearly', (sometimes other) people speak very quickly and then I lose it...I have to put up with it..."

He recalled what it was like with music and drama:

> "...I can hear music better than I can hear speech,..but if there's a play, a drama, a lot of it I miss and, if you miss parts of a drama, you may miss the vital lines and it's ruined, so I don't waste my time listening to plays..."

Telephone conversations and television were no longer as pleasurable for Max as they once had been. Theo also had a frustrating time with the phone especially when she volunteered her services to the local RELATE association and wasn't able to respond appropriately to distraught clients.

However, she felt she managed some fairly successful conversations with her grandchildren in the USA because she had an amplifier on her home phone and they knew how to speak to her. Theo had similar feelings to Max about the television, but her feelings of loss in relation to music appeared to be specifically connected to her piano:

> "The piano I had thought I would sell,..because I don't like to play it now my husband's gone,..(sometimes) it doesn't sound right,...and then I go on, and it...becomes right."

The piano, like her new bed, was another link with Theo's husband, and she was very concerned to do the right thing about it. It appeared that decision making and the autonomy involved became a strain for her sometimes. Again Max had the opposite problem in that he longed for more autonomy. His grandson, Greg,

highlighted how Max's hearing loss could cause mild embarrassment at the family dinner table:

> "...If I say something like,..'Can I have extra tin of peas for lunch?'..my grandad will think it's something (important) and start saying, 'What did you say?'"

As we have seen, meal times with Max and his family were sometimes difficult as family members were uncertain how they could proceed normally, and at the same time be sensitive to their grandfather's feelings of exclusion.

Margaret was right when she said that her father was more comfortable in his own home. There he was able to maintain control and decide what was and was not important 'to hear'.[57] This in turn was likely to facilitate his hearing in that conversations directed towards him were easier to hear than those across him.

While Theo did not regularly interact with her own grandchildren, she helped small children with reading. She explained:

> " I've got a little Asian boy who comes here on Thursday...I can (not) understand what he's saying, but I can guess...(I)... teach...(him) to read...(with) flash cards - I (say), 'Put out all the ones you know and then tell me'. Then I can hear him..."

Theo's confidence in her ability to communicate with small children meant that she could sustain her teaching role despite her hearing loss and the little boy's heavy Asian accent. Theo and Max both reported very little difficulty understanding their own grandchildren as will be described in the next section.

MAX AND THEO AND THEIR GRANDCHILDREN

Max did not feel that his hearing impairment in any way obstructed his relationship with his five grandchildren. He related:

> "Oh I sometimes say to (my younger grandchildren), 'you must go a bit slower'. 'Alright grandad, we'll try again' so they're very cooperative...No I don't think (being deaf) has damaged my relationship with (my grandchildren) at all...they're very loving children... they come and see me just as they would before I was deaf..."

All the grand children had made an effort to relate to their grandfather and he with them with considerable success. In fact Max was able to develop a relationship with each grandchild around common interests, mutual support, or involving tasks which needed doing. While he had difficulty in the family group, Max's experience of life meant that he had acquired an excellent ability to manage intimacy with his grandchildren when they visited him individually.

One of Max's five grandchildren, 13 year old Greg, had acquired a unique perspective of his grandfather's bereavement. He recalled his enjoyment of being with him:

> "I reckon I've got a bit closer to grandad...since my grandma died. I was quite close to her (too)...Now I go down on my own in the evening(s)...and we get on quite well...We just sort of sit...if I crack a joke, he get's it...He understands what I mean...I'll laugh with him, and I...won't let him get away with anything and he never lets me get away with anything."

He had observed changes in his grandfather's behaviour:

> "He sort of looks after us now...before I got to the stage when I could...go out on my own,.. (he would) look after us, and we('d) stay the night, and

we always had boiled eggs and soldiers in the morning...But when grandma died, he didn't cook for himself (or anyone else), he didn't really know how to,..he just sat there..."

As part of the acceptance and integration of Dora's death, Max had identified with her and become more nurturing.[58] This also meant that 'help' was still reciprocal.[59] Margaret explained:

"...my dad helped me out considerably at different times... When the children were a bit younger,..he would always have them if they were ill and I couldn't take the time off,..he would always do other bits of shopping for me locally if I asked him to. It's a bit of a two way thing really, I know that I can rely on him."

Margaret's comments reflected the 'intergenerational solidarity' which Dora had built in to familial relationships.[60] Greg added:

" I think in his own way, he does like his <u>own</u> company... Sometimes we go down there, but...you get the sort of feeling that he's glad when you go as he wants to be quiet, and when you're leaving and there's a good tv programme on that he likes, you sort of say goodbye to him and (he replies) 'bye bye' (and) I sort of laugh inside (when this happens). I know what he likes."

Max's intense manner in watching these programmes was different from other hearing impaired grandfathers in the study. For the latter, there was a fascination with a world they had never experienced; for Max it had been a world that he had experienced, if only for a relatively short time. The literature also takes note of this phenomenon, that is television as link object or compensation.[61]

Greg and Max had developed a unique form of intimacy which a grandfather and grandson could develop when they were similar in temperament, see each other daily, and share marginal adult status.[62]

Theo knew that she had not been as fortunate as Max as her grandchildren had been out of the country. But she was, nevertheless, grateful for what was given:

> "...(My grandchildren) have been back every year since they went away, and I don't have any difficulty hearing them,..well apart from saying 'speak up a little louder: I can't hear your quiet voice'... Yes, (occasionally I have to ask them to repeat)..."

Theo, like Max, could be direct about her need for clear speech from her grandchildren. She described how letters also helped:

> " When Philip writes (his weekly) letter (to me), I can see what the children are doing in the house, what Richard is doing in the garden...the rabbit got out and did something funny - I'm really there with them, and it's wonderful..."

Theo's deep understanding of children's lives generally helped her to fill in the missing blanks in her grandchildren's lives. On the other hand, she was delighted when one actually came for a visit. She related:

> "I didn't know Diana so well until she stayed with me, and...she has <u>the</u> 'organisation'...When she came from Heathrow, she would come to Victoria,...ring me up to say that the train was just leaving Victoria, but she had already booked her coach to Leeds the next day,..she is just how I like..."

Although Theo missed observing the development of her grandchildren first hand, communication flowed across the Atlantic and she was well informed. Her hearing

loss had not been an obstacle in this process because of the family's great facility for writing letters.

SUMMARY

In this chapter, a case study approach was used to focus on the lives of a widow and widower. Both had lost their partners within the last ten years and both had an acquired hearing loss. It emerged that the widower had more difficulty adjusting to bereavement than the widow. This is supported in the literature in that despite men's larger investment outside the home, they nevertheless, often have a deep and enduring relationship with their spouses.

It was necessary for both Max and Theo to experience certain psychosocial processes throughout their bereavements so that they could refocus on their lives, for example, their need to 'accept' their losses with the accompanying sense of 'stigma', 'to identify' with the positive characteristics of their dead partners and 'to integrate' the past reality with the present.

Although Max denied he was coping well, no doubt because he felt so diminished without his wife's support, he made an exceptional adjustment to the circumstances in which he suddenly found himself. Max was helped by the fact that the families of his two daughters lived locally providing support, he had acquired excellent relational skills so that he could relate closely to his family, and he was basically happy with his life choices. The latter meant he could take further risks, for example, his joining of the Selsdon Hard of Hearing Group.

Theo also made an excellent adjustment to her bereavement. As her husband had been an invalid for many years, she was more prepared than Max had been. However, the actual death of her husband was deeply felt as they had managed to transcend disappointments which had occurred earlier in the marriage. Theo was like Max in that they were both outgoing, and thoughtful people who had acquired excellent relational skills. These in turn helped them through their times of loss.

Theo differed from Max in that her 'little bit' of family lived in the USA. This was not to suggest that she was emotionally isolated from them since visits, letters, and telephone calls were exchanged. As it emerged, Theo was in fact very important to her son's family both as it's inspirational 'head', and as a 'half way house' between the USA and the UK. What was missing for her was a more traditional 'tending' of physical needs which took place in Max's family along with the rich relationships which he was able to nurture daily with some of his grandchildren. Theo and Max were thus forced by fortuitous circumstances to reverse what might be traditionally expected. For example, when their respective spouses died, Max found himself surrounded by a protective natural family. Theo, on the other hand, found herself in the midst of an adopted family consisting of neighbours, friends, former colleagues, professionals, tutees and a cat. It emerged that this reversal had its advantages and disadvantages. It meant that Max had to sometimes fight for his autonomy, while Theo seemed occasionally overwhelmed by hers.

The focus of this chapter has been on the complete breakdown of the marital relationship through death and the aftermath of bereavement. The next chapter will examine rehabilitation as a formal and informal process.

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CHAPTER XIII REHABILITATION: A FORMAL AND INFORMAL PROCESS

INTRODUCTION

The discussion so far has focused on the ways in which hearing impairment affects family relationships and the surrounding social network. Throughout, the process known medically as 'rehabilitation' has been an important undercurrent. As the feelings of initial shock and loss subside, people who have acknowledged their hearing impairment are generally able to reinvest themselves in rehabilitation or reconfiguration processes.

In 1958 the World Health Organisation stated that 'rehabilitation' was not only about restoring the disabled person to his previous physical condition, but also about developing fully his physical and mental functions.

Because the 'medical model' was paramount during the 1960's, this definition was initially accepted by social policy and disability scholars, although ideas began to change in the 1970's.[1] The 'medical model' places considerable emphasis on assessing the individual's objective performance audiologically and in terms of their ability to communicate.[2] However, this model is now highly contested by scholars in the disability[3] and Deaf fields.[4]

Oliver and his colleagues argue that the problem does not lie within the individual as the 'medical model' of rehabilitation suggests, but within society at large. In this 'social model' of disability, the problem is removed from the individual and placed in the environment.[5] In the specific case of hearing impaired people, the 'social model' removes the problem from afflicted individuals and focuses on their right of access to spoken English. Oliver and his colleagues find fault specifically with the medical/ rehabilitation model due to it's focus on the issues of 'normality'[6] and 'dependence',[7] which are seen by them to be social constructions. On the other hand, Oliver does accept the need for a time of rehabilitation.

Both the medical/individual model and the social model have valid points, and so this study argues there is much to commend a 'both/and' position which draws from each model when appropriate. The discussion now shifts to a clarification of terms.

ADJUSTMENT AND RE-CONFIGURATION

Jones, Kyle and Wood[8] prefer to speak of 'adjustment' to the acquisition of hearing loss and define it as:

> " (the) change in (the patient's) behaviour, belief, relations, or interaction occurring in the period from the onset of hearing loss whenever that actually is."[9]

This term was adopted in reaction to previous research where rehabilitation models took their place within a psychiatric framework.[10] This apparent obsession with psycho-morbidity studies continued as in the work of Markides[11] and Thomas and Herbst.[12] However, the latter did acknowledge that while their research helped to quantify psychological disturbance, there remains no satisfactory explanation for what it was about hearing loss which made those afflicted so vulnerable to mental illness.

Gradually researchers began to investigate this question with varying results.[13] Of particular interest are the findings of the Bristol team. They concluded that the degree to which an individual can tolerate the reduced and varying access to information at home, socially and at work will determine the degree of 'adjustment'.[14]

While the term 'adjustment' is a more restrained term than 'rehabilitation', it nevertheless, is seen to be unsatisfactory by Oliver[15] and other sociologists and social administrators. They argue that it is also socially constructed and comes from bereavement theory making the assumption that some aspect of the person with a disability has died or is unwell.[16] They feel that this is a simplistic perspective which does not take in the full diversity of the experience of individual disabled people.[17] In other words, some disabled people may actually be very healthy and/or have never felt much grief since they have never known life without their disability.[18]

Yet despite its limitations, the term 'adjustment' most accurately describes the process experienced by the majority of people in this study who became hearing impaired. This process of 'adjustment' was experienced before, or simultaneously with, getting on with their lives. Another term suggested by scholars is 'reconfiguration'.[19] This word focuses on the 'matter of fact' linear nature of a multi - dimensional reshuffle in all processes connected with communication. This reshuffle takes place simultaneously with the gradual awareness of family[20] and friends that there is a hearing impaired member in their midst requiring ETTA (Effort, Time, Thought, Attention).

Although behaviour change inevitably occurs long before a formal diagnosis is made, it is at the time of diagnosis that people begin to meet professional rehabilitators and the adjustment phases begin. In the UK, this is mainly a time of hearing aid provision rather than the intervention of support services. This is not to say that hearing aid provision does not reduce the problem for some people or that surgery and medical treatment are not occasionally sufficient. Rather, it is that middle class English norms[21] dictate that people with problems should live as best they can. Although there are signs that this attitude is changing,[22] people with hearing impairment are at present inclined to forego any professional help that is in fact rightfully and helpfully theirs.[23]

While this discussion is relevant for our understanding of traditional rehabilitation methods, this chapter focuses specifically on the young profession of hearing therapy. As this study progressed, the importance of the specific role and boundaries of hearing therapists emerged suggesting the need for analysis and policy formulation. This emergence is in conjunction with a more general discussion currently taking place between other rehabilitation professionals namely technicians and deaf workers.

First let us analyse the present situation of the profession of hearing therapists, and the historical and political context from which it has developed. Current services will be compared with the more developed services offered in some other European countries. After discussing policy recommendations, the focus will shift to the help given by informal rehabilitators: spouses, significant others, and by the person's own initiative.

HEARING THERAPY IN THE UK: A BLIND INFANT PROFESSION IN NEED OF REHABILITATION?

We must begin by asking what the consequences were of the DHSS's decision to substitute experience and lipreadability for a graduate degree for those seeking entry into the profession of hearing therapy?[24] Firstly, the multi-faceted nature of acquired hearing loss which strikes at the very heart of all human communication was ignored.[25] With the 'medical model' in the ascendant, the nature of acquired hearing loss was reduced to the physical process of not hearing. Secondly, because hearing therapists have only one year of training beyond a secondary education, they lack a rigorous intellectual foundation to their work. This means they have little standing with other more developed professions in this country,[26] and with hearing therapy professionals in other countries particularly Denmark,[27] Sweden,[28] Germany[29] and Holland.[30] However, this is not to suggest that British hearing therapists lack international recognition.[31] Thirdly, it may also be argued that people with acquired hearing loss are best helped by the use of the systems approach in hearing therapy or rehabilitation counselling. This means that the problem is seen not just as an individual one, but as also belonging to the couple and the family.[32]

Consequently, a well - trained hearing therapist's primary task is to facilitate the formation of a 'family therapeutic alliance'.[33] This may be done by using an understanding of the 'therapeutic alliance' concept,[34] the systems approach,[35] and the three family dimensions which form the Circumplex Model of Marital and Family Relations[36] described more fully in Chapter IV. It is the forging of this alliance which is most helpful in enabling 'adjustment'.

It is now appropriate to focus on how the idea of hearing therapy first developed.

HEARING THERAPY's HISTORICAL CONTEXT: THE A.C.S.H.I.P. REPORT

The provisions of the Chronically Sick and Disabled Persons Act[37] highlighted the appalling gap in services for people with acquired hearing loss. This was further

confirmed by the Rawson Report.[38] In September 1974, a subcommittee of the Department of Health and Social Security's Advisory Committee on Services for Hearing Impaired People was asked to consider the rehabilitation needs of the adult hearing impaired. The brief given was to make recommendations specifically in reference to the role of the NHS.

The subcommittee elected to concentrate on the core of the rehabilitation process which was the follow up of patients attending ENT departments. They agreed that it was not sufficient simply to fit a hearing aid and to assume all recipients would automatically and spontaneously acquire a skill in its use. Previous surveys of users of the old Mecresco box hearing aids, had found as many as 39% did not use the hearing aid every day, and that 10% did not use their aid at all. This suggests that the lack of follow - up rehabilitation services for patients with a sensorineural deafness had frequently resulted in severe disappointment, and a further sad waste of individual abilities and public money.[39]

The published report of the sub-committee called for the creation of a class of experienced workers with special training in the skills required. The report detailed the roles, skills, training, personal attributes, qualifications, prospective salary range etc., which would be required by the new worker. The hearing therapists' role was seen to be the assessment of the extent of the disability and the formulation of a rehabilitation strategy. The aim was to raise the patients' communication performance to the maximum possible and to maintain it at this level. This was seen as a very complex process because of the multiplicity of factors involved, namely how much and what kind of residual hearing the patient had, how much innate lipreading ability was possessed, what was their communication lifestyle, what were their social needs, and what was their general motivation to make the adjustments involved. It was further suggested that the assessment would be designed to elicit the patients' own definition of their communication problems; for example, what did the patients regard as difficult situations, and in what circumstances did they arise?[40]

Recommendations made in the body of the report and diagrams found in the appendix suggest that the new profession of hearing therapy was to be seen as one member of a

multi-disciplinary patient care team consisting of a graduate student in audiology, a technician, a teacher of the Deaf, and a speech therapist. They all, in turn, were responsible to the ENT consultant concerned. It was also acknowledged that part of the rehabilitation process might be provided by people from other disciplines outside the ENT department namely psychiatrists, psychologists, health visitors, disablement resettlement officers and family and social counsellors (see Appendix II for Chart). Furthermore, the special problems and needs of hearing impaired people might involve discussions with family members, neighbours, employers, teachers etc.

In evaluating the response of the Department of Health and Social Security to these recommendations, it is important to understand that 1975 was possibly the worst time to publish them. By 1976, as a result of the oil crisis, economic and political ideas had turned a somersault, as social service expenditure which had been increasing since the end of World War II, became severely checked because of the lack of hope in improving overall economic growth.

Some attempt was made, however, to implement the ACSHIP report as the following section explains.

HEALTH CIRCULAR (78)II ESTABLISHES HEARING THERAPY

In 1978, the Department of Health and Social Security considered ACSHIPS's recommendations and issued Health Circular (78)11.[41] It announced the establishment of a new NHS profession called 'hearing therapy'. The most pronounced change from the original recommendations was the qualifications required of the profession. While the ACSHIP report had clearly recommended that training for hearing therapy began at the graduate level, Health Circular (78)11 read, "The post will be suitable for mature candidates with at least two years experience, preferably in the NHS or with a local authority social services department, in working with the deaf or hard of hearing. While no specific academic qualifications are laid down, the training course is an intensive one year course of professional training at higher education standard and is primarily intended to add to previous training and experience in working with Deaf people. An ability to speak clearly and to be lip-readable is essential". Earlier in the

circular it was also noted that, "... a majority of the population (in the UK) would not satisfy such a requirement". [42]

Although it might be argued that the substitution of experience and lipreadability for a graduate degree was an astute practical and financial decision, it was in fact immensely shortsighted. Without rigorous mental training leading to a degree and beyond, hearing therapy lacks an intellectual foundation on which to build and develop. This has consequently led to a narrowing of the service and provoked widespread controversy within the profession as well as outside.

In adopting this position, the DHSS appears to have lost sight of the multi-faceted nature of hearing impairment. It is not just about the physical process of not hearing, nor is it about the frustrations experienced in losing information and social control. It strikes at the very heart of all human communication. Seen from this perspective, the problem is much deeper and more encompassing in that the ability to hear is a primary component in all relational processes especially those within the family. Here we come full circle as many observers see the well functioning family as a cornerstone of participative citizenship.

The literature suggests a more helpful approach which will now be discussed.

USING THE THERAPEUTIC ALLIANCE, FAMILY SYSTEMS THEORY, AND THE THREE DIMENSIONS OF FAMILY LIFE WHEN COUNSELLING PEOPLE WITH ACQUIRED HEARING LOSS

The experience of both clinicians[43] and researchers[44] and the evidence produced in this study indicates that a hearing impairment is often disturbing and stressful to intimate family relationships. Family therapists in their use of the systems approach frequently point out that when objects of a system are actually people in relationship with other people, one of the most important attributes of that system is communication behaviour.[45] This is further confirmed by findings that a disability or illness, especially one involving a barrier to good communication with one member of the family, is likely to have a profound effect on the family as a whole.[46] Conversely, the attitudes of

family members can have a strong influence on the overall adjustment of the unwell member.[47]

As we have seen, Joy's experience revealed this phenomenon. Her sudden deafness caused by meningitis, triggered a major unpredictable family crisis.[48] Besides breakdowns in communication between generations, breakdowns in understanding between partners also emerged as exemplified in Joe and Sarah's fear of intimacy, a problem hidden behind their difficulty in sitting down together so that lipreading could take place.

If counselling had been part of the general rehabilitation programme available to these families, the counsellor would have attempted to build a 'therapeutic alliance' with them. This is done by showing empathy towards the couple along with professional competence in dealing with the problems they present.[49]

For example, Joe and Sarah could have been helped to assess objectively how Joe's hearing loss impinged on their relationship along with other 'differences' which resulted in their disengagement. In this way they could have been shown the falseness of blaming Joe's deafness for all the conflict in the marriage, although it undoubtedly exacerbated it. This approach could have facilitated a more accurate picture of their difficulties, which in turn could have led to the evolvement of a deeper mutual bond.

When members of a family present themselves for counselling, the counsellor attempts to engage everyone in the therapeutic alliance. As a feeling of trust is developed, the counsellor may look with the family at the role of one member's hearing loss in the family system. How does each member of the family feel about it? Can they be honest about their negative feelings, and can they go on to discover positive ways of coping? Some of the issues explored could be concerns about autonomy, intimacy, sense of loss, and stress. The studies' findings suggest that these are specific topics which are often deeply felt, but are difficult subjects to discuss. Also it is important for the clinician to have an awareness of the importance of the family dimensions arising from the Circumplex Model: cohesion, adaptability, and a facilitating communication.[50]

Thus it may be argued that rehabilitation counselling should be available to all people who have an acquired hearing loss. What is actually available?.

CONTEMPORARY HEARING THERAPY

Today hearing therapists are trained to provide individual interactive counselling in that they help hearing impaired persons "explore their own feelings about what has happened to them...(which hopefully) enables them to adjust to it (the event) as much as possible".[51] Although trainees receive 38 hours of counselling instruction during their one year course, most of their training remains more technical and practically based in that it focuses on auditory training, lipreading, speech correction or preservation, and advice on environmental aids such as, flashing light alarm clocks, telephones, and door bells.[52] Recently the organisers of the hearing therapy course at the Centre for Deaf and Speech Therapy (The City Literary Society) have been trying out a new approach. They have introduced the new National Vocational Qualification whereby the students are taking more responsibility for their own learning.[53] While this might improve the quality of training, it in fact, does nothing to remedy the fundamental difficulties inherent in hearing therapy training.

Despite continual progress in updating the hearing therapy course, providing group work with other hearing impaired people and work with some marital partners and families, three major problems remain unresolved. Firstly. the majority of hearing therapists feel that the Department of Health and Social Security were at fault in their Health Circular (78)11 in choosing to ignore the original ACSHIP recommendations, and for finally suggesting that the entry requirements for hearing therapy training should be "candidates with no specific academic qualifications". It is believed that such free entry has no doubt contributed to the poor career and salary structure; and this in turn undermines the hearing therapists' ability to meet fellow therapy professionals on an equal footing".[54] Secondly, there are fundamental concerns among hearing therapists themselves about aspects of the training course namely the general status and length of the course, entry requirements etc., especially compared with other professions using the name therapist (for example, occupational therapy offers a three year programme, speech therapy has a three or four year programme).[55] Thirdly, the

present economic climate and NHS changes have meant that many hospitals are stripping themselves of all but essential services. Because hearing therapy is relatively new and unestablished, it is unlikely to be given priority. Yet the case is otherwise in some other European countries for example Germany,[56] Holland,[57] Denmark and Sweden.[58]

Britain is not alone in entering the field of hearing therapy relatively late. Counselling help for people with an acquired hearing loss in the USA is still 'hit and miss'. There are programmes to train counsellors to work with culturally Deaf people, but there is a tendency for them to be attached to rehabilitation and education programmes rather than social work and mental health. Training for counsellors with specific expertise in the difficulties caused by an acquired loss is just beginning to be recognised as a need.[59]

The country which has probably the most developed programmes for people with acquired hearing loss is Sweden and the focus will move to examine their approach.

SWEDEN: A HOLISTIC APPROACH

The members of the original ACSHIP subcommittee did not see their recommendations as innovative. They were aware that considerable progress had already been made in the Scandinavian countries especially Sweden and Denmark. For a direct comparison with the British system, it is instructive to look in some detail at the Swedish programme for hearing impaired persons. In Sweden, there is an extensive programme of local auditory services which provide assistance to people with acquired hearing loss. Besides this, there is a National Labour Employability Institute based in Uppsala with special resources for disabled people specifically for those with hearing impairment.[60] It is financed by the Swedish Government and the programme offers hearing rehabilitation combined with vocational rehabilitation and employment counselling. The activities of the Institute aim to eliminate recurrent difficulties and prepare for problems in employment primarily in the regular labour market.

When a hearing impaired person arrives at the Institute, they are asked to spend three days talking to several professional experts who assess them from different perspectives. As this is done, a treatment plan is developed with concern for the whole person. A hearing therapist will check the person's hearing aid. It will be exchanged for a new one if it is not appropriate. The speech therapist will examine speech production and speech reading. If there are other physical problems such as tinnitus, a medical audiologist will discuss ways in which this might be helped. If the hearing impaired person suffers from stress and tension, the physiotherapist may help with relaxation exercises.

As there is a strong understanding of the psychosocial consequences of hearing impairment, the person will meet a social adviser and psychologist. This is often followed by the person's family arriving for a 'Family Day'. At this time it is hoped that family members will deepen their knowledge and understanding of some of the problems which the person has to face. The person is often asked to write down their own expectations of themselves. If they feel they fall short in some way, the psychologist may offer some supporting short term psychotherapy. If the person has progressed this far, they will then be encouraged to take part in employment counselling discussions with a small group of other hearing impaired persons. Once the person establishes the kind of job they would like, counsellors work with the local labour exchange so that appropriate training and eventual job placement takes place. When this has occurred, the hearing impaired person is discharged from the Hearing/Employability Institute, but may receive further counselling and support at the local level.

Although every rehabilitation programme has its limitations, the Swedish programme, which offers both intensive and long term help, has a high rate of success in returning hearing impaired people to their homes and new jobs with improved functioning and confidence.[61] This suggests definite advantages in the holistic approach when a person has a hearing impairment.[62] It is important to clarify that in focusing on Sweden, it is not being suggested that the UK is entirely without holistic treatment centres for hearing impaired persons. The rare places where such treatment does exist are either registered charities with very specific goals such as the Link Centre in Eastbourne, or

experimental collaborative programmes with regional health authorities and social services such as the Birmingham Centre for Deafened People. Neither programme has the secure government financial backing which may be found in some European countries.

Given the cultural and historical differences in the development of Continental European welfare states, particularly the frequency with which their benefits are conditionally linked to labour market participation, it is unlikely that Britain will go fully down the Swedish road in the near future. Currently, Sweden is undergoing a programme of privatisation designed to cut costs and to increase the choices of recipients of social service provision. How exactly this will affect services to those who are hearing impaired remains to be seen.[63] Nevertheless, we can learn from the contrasts in service provision found in the two countries. There are questions about the use of time and money, the training and use of professional personnel, and the profile of hearing impaired persons generally. Among the many questions which could be explored, two particularly stand out. Firstly, why is it that a hearing therapist in England may be given one year of training with an undefined theoretical foundation after secondary education before becoming qualified, while therapists working with hearing impaired people in Sweden, Denmark, Holland and Germany, are required to attend a much longer period of training?

Here it is helpful to make a more precise comparison with the 'hearing pedagogues' of Denmark. Pedagogues must all be qualified teachers (four year college training and/or university education) with an additional 14 months specialised training in the education of hard of hearing children. The Swedish have a similar requirement for their hearing therapists. Most hearing therapists have an education as a teacher for about two years. After a certain period of time teaching, they may add a special training (diploma), learning specific details about hearing impairment. Three terms of further study are required for working with hearing impaired persons, and four terms for working with Deaf people.

Secondly, why is it that a hearing impaired person in Sweden is encouraged to talk to a team of six to eight professionals while in the UK, a person with the very same

problem is considered fortunate to encounter one dedicated, but over - worked and under - trained hearing therapist? So far in Britain, only 70 therapists have been trained out of the 200 originally recommended.[64]

Whatever the response to these questions, evidence for the need to reform the current system is clear in the case of the present study.

While the profession of hearing therapy has fallen short in certain important aspects, some success has been achieved specifically in working with the elderly. We will now consider a way forward.

A WAY FORWARD

Perhaps the way forward for hearing therapy may actually be achieved by looking backwards. It is important to regain a deeper understanding of what was lost from the ACSHIP report in 1975. Hearing therapists at that time were regarded as having a trifocal role namely 1) the assessment of a hearing disability incorporating the views of the patient; 2) setting up a rehabilitation strategy, and 3) referral to other professionals when appropriate.

Currently, very few referrals occur. This may be partly the fault of the ENT consultant if he has little understanding of the help which hearing therapists are trained to give when available. On the other hand, it may be the result of the insufficient training of the hearing therapists which has not equipped them with the skills to deal with the multi-faceted nature of deafness. The more skilled therapists are just beginning to be able to recognise when a problem (for example, low self esteem) is connected with a hearing loss or when its roots lie elsewhere. Rather than discriminate what they can and can not do well, hearing therapists are currently behaving like 'jacks of all trades', and attempting to do everything for hearing impaired people. This understandably lowers the professional development needed to provide good rehabilitation services and keeps their work at a primitive level. Consequently, if they are to move forward as a profession, a much clearer more sophisticated boundary has to be built around their theoretical foundations and field of practice. It is only then that they will be on an

equal footing with other professionals which will facilitate good referrals by members of the ENT team as well as to outside professionals as recommended by the ACSHIP report. On the other hand, related professionals need to acquire a deeper understanding of the communication problems specifically caused by the nature of acquired hearing impairment so that they will be ready to accept referrals when the time comes.

Secondly, as suggested in the marital and family therapy literature, a communication problem belonging to one member of a partnership or family in effect belongs to the whole kin network. If the responsibility of rehabilitation becomes a challenge for both the couple and the family, the negative aspects of the disability (for example irritability when unable to hear) have a much greater chance of being transformed.[65] In this respect, there is much to learn from the Swedish system with their 'family days'. Clinical and research evidence suggests that family involvement may no longer be seen as a mere option in rehabilitation work, but as an early and fundamental requirement. This is supported by Jones, Kyle and Wood when they say:

> "the resources available to hearing therapists have been totally inadequate. Hearing people are participants in hearing loss and need to be involved overtly in the adjustment process. Their involvement should occur as soon as hearing loss is suspected..."[66]

Thirdly, every effort should be made to recruit hearing impaired people as hearing therapists. As research suggests,[67] equal status of interviewer and interviewee is likely to facilitate a more honest and helpful exchange of information thereby leading to a better provision of service. However, there are other factors besides status alone operating in a user/provider relationship. This suggests that whether deaf or hearing, hearing therapists require good supervision if staff development is to occur.[68]

Perhaps if hearing therapists and other related professionals became more united in their understanding of the importance of the problems of people with acquired hearing loss, a stronger joint effort could be made to consolidate their resources, experiences and skills. With this additional support, hearing therapists would be in the position to

expand their own existence, improve training, status, career structure, professional knowledge, and methods. The eventual outcome of all these improvements would be the establishment of an adequate rehabilitation service for the ten million people with acquired loss in the UK.

Hearing therapists in the UK are not given sufficient training. Comparisons are made with European countries where a greater investment is made to help hearing impaired people. It is possible that hearing therapists could evolve in this direction to the extent of creating a new position. These new workers would synthesise some of the 'therapeutic' aspects of the English model of hearing therapy with the 'pedagogic' approach found in Denmark.

The systems perspective, although not without fault, for example, in that it does not sufficiently address gender issues,[69] seems to offer the most promising theoretical framework for hearing therapists who could implement it by involving members of the immediate family regardless of the fact that only one of its members actually has a hearing loss. The purpose behind this strategy is to encourage the collaboration of the family in the rehabilitation process or a 'family therapeutic alliance' which could expand to become a 'family friendship therapeutic alliance' so that obligations and enjoyment, duty and choice, may ideally be contained together within marital and family boundaries and revitalised over time.

Two explicit social policy issues arise from this discussion. Firstly, what is the best institutional framework in which to provide adequate rehabilitation services: hospitals, in the community care programme, or in other institutes or centres as found in Scandinavia? Secondly with the introduction of the quasi-market to the NHS, and the provision of many services by the private sector, how should the services be best coordinated?

If it is the case that some of the formal rehabilitators are not doing an adequate job, how are rehabilitation/reconfiguration processes being managed? Let us now consider the experiences of people interviewed in this respect.

INFORMAL REHABILITATORS

Study participants often mentioned professionals who were not their formal rehabilitators; for example help was given by a psychotherapist, a psychiatrist, a speech therapist, a homeopathic doctor, a singing teacher, a marital therapist, a head teacher, and a Methodist minister. Most of these people operated in hearing settings, and could be seen to overlap with the first level of social support.[70] While the literature[71] argues that it is the informal rather than the formal social support networks which are the most crucial to families where there is a disability, this study suggests that the situation is far more complex.

It appeared that the boundaries between formal and informal care had merged in certain families. Four out of the sixteen hearing impaired people in the study had married a spouse in a rehabilitation related profession. For example, Barbara had married Ben, a lawyer interested in disability issues; Joe had married Sarah, a lipreading teacher; Henry had married Kay, a teacher of English as a foreign language; and Arthur had married Gwen, an infant teacher who knew BSL and hoped to become a teacher of Deaf children. Another seven people in the study had married 'wise others'[72] in that they were people who were already aware of strategies for managing stigma and loss. They had sufficient internal and external resources to cope without resentment with the extra emotional demands of having a hearing impaired spouse.

The question may be asked how it was that a quarter of the hearing impaired people in the study married partners in the rehabilitation field? Such marriages certainly assured a certain 'place' for 'deafness' within the boundaries of the marriage. Conversely, the hearing impaired spouse could give a certain credibility to the career of the rehabilitation professional. Moreover, the rehabilitation specialist would 'know' about the problems without its implications having to be articulated. This ideally would save energy, time, and embarrassment for the hearing impaired spouse.

Yet, the reality observed in these relationships was more complex. With some couples, there was danger of emotional overload for the rehabilitation professional when being 'at home' was too much like being 'at work'. Considerable objectivity had to be

maintained so that the boundaries between the two spheres were clear. Lastly, additional stress could be felt by the helping professional because of self imposed high expectations of always being the 'expert'.[73]

The focus now shifts to more traditional ways of caring.

INFORMAL REHABILITATION AND RECONFIGURATION: SIGNIFICANT OTHERS AND SELF

Ideally the goal of medical and psychosocial rehabilitation is for the responsibility of its administration to be taken on by the patients themselves and in this way outgrow their patient role.[74] A common feature of most of the people interviewed was their willingness and ingenuity in doing this. As we have seen some took up old interests with slight alterations, while others discovered new activities. The most noticeable characteristic of these activities was the enormous variety and range they represented. The three most commonly mentioned interests were going on foreign holidays, religion and the development of a deep faith, and watching television. Not surprisingly, all three activities have a strong visual component. Other more individual interests included operating Hornby trains, astrology, leading a sign language choir, meteorology, being a remedial reading teacher, viewing art exhibitions, DIY, economics, self sufficiency, the Labour Party, and reading. Even music and taking up a foreign language were mentioned.

As part of the rehabilitation process, clinicians and researchers see socialisation with other hearing impaired people as one factor in promoting psychological health.[75] Thirteen out of the sixteen hearing impaired people interviewed in the study had contact with other hearing impaired people through sign language classes, self help groups, or as hearing impaired/deaf charity administrators. However, this contact ranged considerably from being very superficial to a deep commitment, perhaps a reflection of the acknowledged ambivalent attitude of stigmatized members of society to 'their own'. [76]

Generally it may be concluded that rehabilitation/ reconfiguration processes are continuing, long lasting, and that few generalisations can be made about what particular individuals ought to do in order to become well 'adjusted' as hearing impaired people. It is partly because of this individualistic nature of the process which makes appropriate counselling so important.

SUMMARY

The focus of this chapter is the formal rehabilitation services for hearing impaired people in the UK, specifically their historical/political context and their role, and the boundaries of the young profession of hearing therapy. Compared with other European countries such as Denmark, Sweden, Germany, Holland, and the USA, it was found that although some advances in the UK have been made, especially in the provision of hearing aids, the UK still lacks adequate training for hearing therapists.

The situation resulted from the decision in Health Circular (78)11 which disregarded their subcommittee's recommendations. The consequence of this downskilling of hearing therapy is an attempt to undertake rehabilitation in too limited a context, ignoring the multi-facilitated nature of hearing loss and the need to engage in a holistic way with many aspects of life. British hearing therapists lack standing with other professionals at home and with hearing therapists abroad.

The primary task of a well trained hearing therapist should be to facilitate the formation of a 'family friendship therapeutic alliance' by effectively using an understanding of the systems approach and the three family dimension: cohesion, adaptability and a facilitating communication. The role of hearing therapists could evolve to a new position altogether. This would combine the 'therapeutic' aspects of their present role with the 'pedagogical' aspects found in the broader Danish model. However, it is doubtful whether the English system could ever completely abandon the medical model which has the ENT consultant in the centre of the treatment team as shown in the 1975 diagram submitted by the ACSHIP report.

The focus of the thesis now shifts to a closer look at the psychosocial constructions of 'deafness as a difference' provided by the people in the study.

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CHAPTER XIV: AN OVERVIEW OF THE SHARED PERCEPTION OF HEARING IMPAIRMENT WITHIN COUPLE RELATIONSHIPS

INTRODUCTION

While we have explored the couple relationships in this study before and after 'couple acknowledgement', we will now develop an overview of the psychosocial constructions of all eleven relationships in an effort to discover which factors were most crucial in facilitating more positive or negative constructions and perceptions of deafness as a difference.

In order to provide a context for this overview, it is helpful to review the study's working hypothesis which is that couples who contain a hearing impairment within their marriages need to assess how it is affecting the quality of couple and family relational processes. If this is not done on some sort of regular basis as the family develops throughout the life cycle/course, it is likely that these processes will deteriorate or not develop appropriately. This hypothesis was very general and dependent on the degree of hearing impairment and the age of onset.

While the literature argues that marriage/partnerships between hearing and hearing impaired people are rarely mutually satisfying, and therefore more likely to deteriorate,[1] it emerged in this study that such marriages were in fact 'good enough' if a certain 'quality factor' develops despite and/or because of a mild to profound hearing loss within the relationship.

Consequently, although adjustment to acquired hearing loss is associated with the time of onset and the degree of loss,[2] as we have seen throughout the study, psychosocial factors, specifically those found in intimate relationships, may in fact be as important, if not more important, than medical factors in predicting long term adjustment. This is because couples who have an unconscious 'couple fit',[3] are able to psychosocially construct reality together.[4] In other words, they develop a 'shared perception' of the way the hearing loss functions within their relationship.[5] This shared perception

focuses on their 'differences' as part of an anthropological/cultural model,[6] rather than on illness or maladjustment as found in a medical model.[7]

CHART OF SPOUSAL SHARED PERCEPTIONS (SSP)

The highly personal perceptions of the eleven couples in the study were put on a chart of Spousal Shared Perceptions (SSP) (See Chart I). The purpose of the chart is threefold: Firstly to classify into groups the shared perceptions of 'deafness as a difference' and to see what characteristics each group has in common. Secondly, to assess whether the hearing loss is perceived as a major or minor factor in life style, plans and goals of the couple. Lastly, to determine what factors within the couples' lives bring about a change in the couple's shared perception of 'deafness as a difference'. It is then hoped that this analysis will provide more effective insights for counselling intervention.

THE PLUS FACTOR

Along the positive to negative axis, four groups emerged. The first group was made up of two couples who had psychosocially constructed the meaning of 'deafness as a difference' so that it was seen positively or 'the plus factor' (PF). For example Arthur and Gwen had the shared perception that Arthur's loss was 'respectable and OK'; while Anthony and Clare saw Anthony's deafness as a 'blessing although sometimes problematic'.

The question was then asked what Arthur and Gwen and Anthony and Clare had in common which would indicate why they were able to perceive 'deafness as a difference' in such positive terms?

Medically, Arthur and Anthony appeared to have had opposite experiences with Arthur, congenitally deaf, and growing up in a Deaf family; while Anthony, from a Nigerian family, was suddenly deafened at age 31.

However, from a psychosocial perspective, these two couples have many similarities. For example, the 'quality factor' is found in the relationships of both couples. Specifically, both the hearing impaired and hearing partners have succeeded to a certain degree in integrating 'deafness as a difference' within the boundaries of their marriages. None of the four individuals involved needed to make use of the psychological defence of 'denial' which meant that true acceptance and compassion could develop.

Secondly, from an anthropological/sociological perspective, both couples understand how to manage oppression and 'outsider status' constructively. In practical terms, this meant that Arthur and Gwen and Anthony and Clare already had initial social networks and self help groups in place which more or less accepted both the deafness, and the deaf and hearing partner as a couple. This meant that both couples were protected from the socially constructed negative attitudes of the dominant hearing culture towards people who are deaf,[8] as well as negative attitudes towards couples where one partner is an 'outsider'.[9] Because these two couples felt a certain security with themselves as a couple, they could get on with their lives immediately despite the hardness of the deaf experience.

INDIFFERENT FACTOR

Five couples were classified as belonging to the next group where the meaning of 'deafness as a difference' was perceived by the couples as an Indifferent Factor (IF). IF was broken down into two subgroups on the basis of how well the hearing impairment was emotionally integrated in to the marriage and/or whether the 'quality factor' was present. Deeper analysis revealed that Sam and Julia and Rachel and Richard, who had perceived 'deafness as a difference' in their relationships to mean 'a stress factor' and 'a nuisance' respectively, had fully integrated the hearing loss and its implications into their relationships. The fact that Sam was profoundly deaf and Rachel had a mild/moderate loss did not appear to be factors which influenced the couple's shared perception and the integration process. A certain degree of acceptance and compassion was needed in all cases.

The second subgroup was composed of Henry and Kay, Barbara and Ben, and Frank and Simone who had perceived 'deafness as a difference' to mean respectively 'an insignificant factor', 'a frustration', and 'an occasional source of sadness'. Although these partners talked openly about 'deafness as a difference' within their relationship, it was observed that a collusion process took place. The hearing spouses, for whatever reason, experienced the deafness as too negative to be fully integrated into their marriages. Consequently, many of the implications of deafness such as the need for extra emotional support and understanding, were pushed outside the marriage boundaries. For example, Barbara was an executive of a Deaf charity and Henry was training to be a chaplain of the Deaf; but rarely could either bring the daily difficulties of 'being deaf' inside the boundaries of their marriage for acceptance by their hearing partner or their children. This added to their personal isolation and meant that their hearing family members lacked the enhanced perspective of seeing their deaf family members as being both similar to and different from themselves.

Evidence suggests that difficulties in integrating 'deafness as a difference' are more likely to be present when the partners have a late onset hearing loss within their relationship, when they have married late, and when their social networks are underdeveloped. In these cases, it appears that there are insufficient amounts of what researchers claim to be essential for optimally functioning families that is 'adaptability, cohesion' and a 'facilitating communication'.[10] It is specifically these family dimensions which encourage integration and are therefore part of the 'quality factor'.

MINUS FACTOR

A 'Minus Factor' (MF) is represented by the third group which emerges on the chart of Shared Spousal Perceptions (SSP). It contains Anne and Adam, Sarah and Joe, and Mary and Robert who psychosocially constructed the meaning of 'deafness as a difference' to mean respectively' a problem to be watched', 'a communication problem', and a 'challenging problem'.

This group is distinctive because the hearing partners are more consciously aware than in other groups, of their strong caring function within their partnerships. This function

was articulated by Sarah and conceptualised in this study as ETTA, the Effort, Time, Thought and Attention required by the hearing partner when communicating with their hearing impaired spouse, (specific roles undertaken may be found in Chart 4). Although ETTA was operating implicitly with other couples, there was less consciousness of it. There was also some shifting towards and away from this group. For example, although Anthony and Clare claimed Anthony's deafness was a positive factor, it's problems were emerging daily. While Julia and Sam saw his hearing loss as one 'stress factor' in their lives resulting in an Indifferent Factor classification, there remained the possibility that it would become more problematic if they were to have children. The latter example suggests that family transitions of any kind are likely to make couples revise their shared perception of 'deafness as a difference', and that it is likely to shift down the axis until a new equilibrium is found.[11]

However, in acknowledging the validity of the ETTA factor, it must also be acknowledged that the couples' relationships are interdependent as illustrated in Chart 5.

FAMILY CRISIS FACTOR

The last grouping to emerge is sudden deafness experienced as a Family Crisis Factor (FCF). Mike and Joy perceived the meaning of 'deafness as a difference' in their relationship to be a 'shared burden'.

The question was then asked in what ways were Mike and Joy different from other couples so that their psychosocial construction was more negative? It was certainly not their basic relationship as they were a particularly well suited couple, enjoying each other's company in both work and leisure. After deafness struck Joy twelve years into their marriage, they continued to maintain their shared perspective because Joy was an excellent lip reader and Mike was a natural communicator. The researcher went so far as to rate Mike as a 'high adjustment' husband[12] in that he not only allowed Joy's deafness to be fully integrated into the marriage so that the 'quality factor' was present, but he also took an interest in the intellectual and technical aspects of her

condition. Two other deafened women in the study, now divorced, were not so fortunate.

While Joy kept her husband by her side together with a number of devoted friends, her sudden deafness meant that she had experienced a number of crucial losses. These were her loss of social autonomy,[13] capacity for intimacy with her only son,[14] of status[15] and feelings of marginalisation[16] in that she was no longer her husband's business partner. These specific losses tainted what was given and lowered her enjoyment of life resulting in the more negative joint perception of deafness as a difference'.

SUMMARY OF FINDINGS FROM THE SSP CHART WITH ACCOMPANYING CHARTS 2-6

The purpose of devising Chart I (SSP) is to investigate how perceptions of the meaning of 'deafness as a difference' in eleven couples compared to one another. Some general and some specific conclusions are made.

It emerges that five couples considered that 'deafness as a difference' had not made a major impact on their lives together. This is the Indifferent Factor (IF). The remaining six couples felt that 'deafness as a different' had made a major impact on their lives and they form the Plus Factor (PF), the Minus Factor (MF) and the Family Crisis Factor (FCF).

These highly personal psychosocially constructed meanings appear on the whole unrelated to the time of onset and the degree of loss (See Chart 2 and 3). However, they may relate to whether the deafness was present at the time of couple acknowledgement as it would be seen as part of the attraction (See Chart 6).

In Chart 6, an attempt has been made to reconstruct the relationships of the five single hearing impaired people in the study. Their missing hearing partners left the relationship either through death or divorce. The psychosocial constructions of this group were found to be 'a complaint', 'a sign of old age', 'an isolating problem', 'an

unshared burden', and an 'intolerable burden'. Three out of the five couple perceptions in this group are at the negative end of the SSP spectrum.

In viewing all 16 psychosocial perceptions, it emerges that two negative perceptions on the SSP scale occurred when the hearing loss was mutually recognised before partnership acknowledgement. This is in comparison with five negative perceptions which emerged when the hearing loss occurred after partnership acknowledgement. This may suggest that couples who mutually recognise 'deafness as a difference' within their partnership at the time of acknowledgement are more likely to acquire the 'quality factor' than relationships where the deafness is not part of the original attraction.

It is also of interest that seven out of the 16 couples construed the deafness in their relationship as being an Indifferent Factor or at the positive end of the SSP scale. While this might indicate that there is a strong 'quality factor' operating, the actual findings are more complex. For example, it is shown that the second group of IF couples (7, 8, 9) are indifferent as a partial defense mechanism. In other words, an unconscious collusion takes place with these couples where the hardness of being hearing impaired is not integrated within the marriage and had to be largely managed outside. There also seems to be a connection between the use of this 'splitting' defense and late marriages and/or late onset suggesting that the adaptability required is less likely to be present in later life.

Another trend in the analysis is that couples are likely to shift up towards the positive end of the axis after they have a certain time to get used to living with 'deafness as a difference' within their relationships. Couples are likely to shift towards the negative end of their perceptions at the time of family transitions such as the birth of a baby, children leaving home, or retirement.

It is hoped that the use of the chart of Shared Spousal Perceptions will encourage helping professionals who work with couples where 'deafness is a difference' to become more sensitive to the very complex issues involved. More specifically that

they will help both partners grow in acceptance and compassion and build the 'quality factor' of acceptance and integration in to their marriage.

We now move to the concluding chapter which contains a summary of the most important arguments found in the thesis together with a consideration of its limitations and some suggestions for further work.

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CHART 1 **SPOUSAL SHARED PERCEPTIONS** **(SSP)**

LABEL	PF PLUS FACTOR +	IF INDIFFERENT FACTOR		MF MINUS FACTOR -	FCF FAMILY CRISIS FACTOR	TOTAL NUMBER
SHARED PERCEPTIONS OF 'DEAFNESS AS A DIFFERENCE' IN MARRIAGE/PARTNERSHIPS OF PEOPLE STUDIED	1 RESPECTABLE AND OK 2 A BLESSING BUT SOMETIMES PROBLEMATIC	3 A STRESS FACTOR 4 A NUISANCE	5 AN INSIGNIFICANT FACTOR 6 A FRUSTRATION 7 AN OCCASIONAL SOURCE OF SADNESS	8 A PROBLEM TO BE WATCHED 9 A COMMUNICATION PROBLEM 10 A CHALLENGING PROBLEM	11 A SHARED BURDEN	11
CHARACTERISTICS						
LEVEL OF DENIAL	LOW	LOW	MEDIUM	LOW	LOW	
LEVEL OF ACCEPTANCE	HIGH	HIGH	MEDIUM	MEDIUM	HIGH	
LEVEL OF INTEGRATION	HIGH	HIGH	MEDIUM	MEDIUM	HIGH	
KIN NETWORKS	VERY SUPPORTIVE	MIXED SUPPORT	MIXED SUPPORT	MIXED SUPPORT	MIXED SUPPORT	
FRIENDSHIP NETWORKS	VERY ACTIVE	VERY ACTIVE	LESS ACTIVE	VERY ACTIVE	VERY ACTIVE	
PARTICIPATION IN SELF-HELP GROUPS	ACTIVE	LESS ACTIVE	LESS ACTIVE	ACTIVE	ACTIVE	
THE HEARING PARTNER'S ATTITUDE TOWARD 'CARE'	EASY GOING	EASY GOING	EASY GOING	ETTA FACTOR	EASY GOING	
NATURE OF LOSS PERSONALLY FELT BY DEAFENED PARTNER	AUTONOMY	NONE	BEING NORMAL	BEING NORMAL	AUTONOMY AND INTIMACY	
HOPE FOR THE FUTURE	HIGH	MEDIUM	MEDIUM	MEDIUM	MEDIUM	

CHART 2 DEGREE OF HEARING LOSS RELATED TO SPOUSAL SHARED PERCEPTIONS OF IMPACT OF HEARING LOSS ON THEIR RELATIONSHIP

DEGREE OF HEARING LOSS	LABEL	PF PLUS FACTOR +	IF INDIFFERENT FACTOR		MF MINUS FACTOR -	FCF FAMILY CRISIS FACTOR	TOTAL NO.
	Shared perceptions of 'deafness' as a difference in marriage/partnerships of people studied	1 Respectable and ok 2 A blessing but Sometimes Problematic	3 A stress factor 4 A nuisance	5 An insignificant Factor 6 A frustration 7 An occasional Source of Sadness	8 A problem to be Watched 9 A communication Problem 10 A challenging Problem	11 A shared burden	11
PROFOUND/TOTAL							
Joy						✓	
Sam			✓				
Arthur		✓					
Anthony		✓					
SEVERE							
Barbara				✓			
Joe					✓		
Henry				✓			
Robert					✓		
MILD/MODERATE							
Anne					✓		
Frank				✓			
Rachel			✓				

CHART 3 TIME OF ONSET OF HEARING LOSS RELATED TO SPOUSAL SHARED PERCEPTIONS OF IMPACT OF HEARING LOSS ON THEIR RELATIONSHIP

TIME OF ONSET OF HEARING LOSS	AGE	LABEL	PF PLUS FACTOR +	IF INDIFFERENT FACTOR		MF MINUS FACTOR -	FCF FAMILY CRISIS FACTOR	TOTAL NUMBER
		Shared perceptions of `deafness as a difference' in marriage/partnerships of people studied	1 respectable and Ok 2 a blessing but Sometimes Problematic	3 a stress Factor 4 a nuisance	5 AN INSIGNIFICANT FACTOR 6 A FRUSTRATION 7 AN OCCASIONAL SOURCE OF SADNESS	8 A PROBLEM TO BE WATCHED 9 A COMMUNI-CATION PROBLEM 10 A CHALLENGING PROBLEM	11 A SHARED BURDEN	11
BEFORE EDUCATION								
Barbara	Birth				✓			
Henry	Birth				✓			
Arthur	Birth		✓					
Joe	Infancy					✓		
AFTER BASIC EDUCATION								
Sam	18			✓				
Rachel	26			✓				
Anthony	31		✓					
Joy	37						✓	
Anne	38					✓		
AFTER MAJOR LIFE CHOICES MADE								
Frank	56				✓			
Robert	58					✓		

CHART 4 **COMMUNICATION ROLES OF HEARING PARTNER**

ROLES OF HEARING PARTNER ON BEHALF OF HEARING IMPAIRED PARTNER	INTERPRETER	ADVOCATOR	EDITOR	PROMOTER	MEDIATOR	BUFFER
Mike (H) & Joy (P)	✓	✓		✓		✓
Julia (H) & Sam (P)	✓		✓	✓		
Ben (H) & Barbara (S)	✓			✓		✓
Sarah (H) & Joe (S)	✓	✓		✓	✓	
Kay (H) & Henry (S)	✓		✓	✓		
Gwen (H) & Arthur (P)	✓	✓		✓		
Adam (H) & Anne (M)	✓			✓		
Simone (H) & Frank (M)						
Mary (H) & Robert (S)	✓					✓
Richard (H) & Rachel (M)	✓				✓	
Clare (H) & Anthony (P)	✓				✓	✓

H = Hearing

P = Profound/total deafness

S = Severe hearing loss

M = Mild/moderate hearing loss

CHART 5 **PRACTICAL ROLES OF HEARING IMPAIRED PARTNER**

PRACTICAL ROLES OF HEARING IMPAIRED PARTNER IN MARITAL RELATIONSHIP	DOMESTIC HELP	BREADWINNING (PAY)			PARENTING		GRAND- OR STEP-GRAND PARENTING SUPPORT	SPOUSAL SUPPORT
		Higher than partner	Same as partner	Lower than partner	Primary Parent	Supportive Parent		
Joy (P) & Mike (H)	✓			✓	✓			✓
Sam (P) & Julia (H)	✓	✓			No Children			✓
Barbara (S) & Ben (H)	✓			✓	✓			✓
Joe (S) & Sarah (H)	✓		✓		No Children		✓	✓
Henry (S) & Kay (H)	✓			✓		✓		✓
Arthur (P) & Gwen (H)	✓			✓		✓		✓
Anne (M) & Adam (H)	✓			✓	✓			✓
Frank (M) & Simone (H)	✓	✓				✓	✓	✓
Robert (S) & Mary (H)	✓	✓				✓	✓	✓
Rachel (M) & Richard (H)	✓		✓		✓			✓
Anthony (P) & Clare (H)	✓		✓			✓		✓

H = Hearing
P = Profound/Total Deafness
S = Severe Hearing Loss
M = Mild/Moderate Hearing Loss

CHART 6A

TIME OF ONSET OF HEARING LOSS RELATED TO SPOUSAL SHARED PERCEPTIONS AT THE TIME OF PARTNERSHIP ACKNOWLEDGEMENT

ONSET OF HEARING LOSS IN RELATION TO THE TIME OF PARTNERSHIP ACKNOWLEDGEMENT	PF PLUS FACTOR +	IF INDIFFERENT FACTOR		MF MINUS FACTOR -	FCF FAMILY CRISIS FACTOR	TOTAL NUMBER
	1 RESPECTABLE AND OK 2 A BLESSING BUT SOMETIMES PROBLEMATIC	3 A STRESS FACTOR 4 A NUISANCE 5 A COMPLAINT 6 A SIGN OF OLD AGE	7 AN INSIGNIFICANT FACTOR 8 A FRUSTRATION 9 AN OCCASIONAL SOURCE OF SADNESS	10 AN ISOLATING PROBLEM 11 A PROBLEM TO BE WATCHED 12 A COMMUNICATION PROBLEM 13 A CHALLENGING PROBLEM	14 A SHARED BURDEN 15 AN UNSHARED BURDEN 16 AN INTOLERABLE BURDEN	16
BEFORE ACKNOWLEDGEMENT						
Gwen & Arthur	✓					
Julia & Sam		✓				
Sarah & Joe				✓		
Kay & Henry			✓			
Barbara & Ben			✓			
Grace & George*					✓	

* restructured relationship before the breakdown of intimacy

CHART 6B

TIME OF ONSET OF HEARING LOSS RELATED TO SPOUSAL SHARED PERCEPTIONS AT THE TIME OF PARTNERSHIP ACKNOWLEDGEMENT

ONSET OF HEARING LOSS IN RELATION TO THE TIME OF PARTNERSHIP ACKNOWLEDGEMENT	PF PLUS FACTOR +	IF INDIFFERENT FACTOR		MF MINUS FACTOR -	FCF FAMILY CRISIS FACTOR	TOTAL NUMBER
	1 RESPECTABLE AND OK 2 A BLESSING BUT SOMETIMES PROBLEMATIC	3 A STRESS FACTOR 4 A NUISANCE 5 A COMPLAINT 6 A SIGN OF OLD AGE	7 AN INSIGNIFICANT FACTOR 8 A FRUSTRATION 9 AN OCCASIONAL SOURCE OF SADNESS	10 AN ISOLATING PROBLEM 11 A PROBLEM TO BE WATCHED 12 A COMMUNICATION PROBLEM 13 A CHALLENGING PROBLEM	14 A SHARED BURDEN 15 AN UNSHARED BURDEN 16 AN INTOLERABLE BURDEN	16
AFTER ACKNOWLEDGEMENT						
Joy & Mike					✓	
Simone & Frank			✓			
Rachel & Richard		✓				
Mary & Robert				✓		
Anne & Adam				✓		
Clare & Anthony	✓					
Dora & Max*		✓				
Theo & Will*		✓				
Kay & Fred*				✓		
Christine & Jack*					✓	

* restructured relationship before the breakdown of intimacy

CHAPTER XV CONCLUSION

INTRODUCTION: THE STUDY AND ITS LIMITATIONS

This is a small cross-sectional qualitative study. It is small because the sample interviewed contained 55 people, 28 of whom were children. It is cross-sectional rather than longitudinal as families were studied at seven distinct points in the family life cycle. It is qualitative and not quantitative as the method was descriptive and the focus was on unexplored psychosocial phenomena. Because of these characteristics, it is not possible to make generalisations to all families where one parent is hearing impaired as the findings in the study represent 'snapshots' of families as they were at one particular time.

Nevertheless, this does not mean that the selection of such a research group need only be arbitrary and the findings have no relevance outside those particular individuals. We can learn from 'the micro' as embodied in family life, and make suggestions and generalisations which may apply to 'the macro' or society as a whole. The fact that a group cannot technically be described as a representative sample does not automatically define it as unrepresentative.

Those interviewed represented a very large range of people medically and developmentally. The people involved came from a wide range of backgrounds in terms of class, education, ethnicity and religion.

HEARING LOSS AND FAMILY LIFE

Hearing loss is widespread in our society. It effects every aspect of life where communication is necessary. There are ramifications for every level of daily life whether it is talking to one's partner in bed with the light out at night or being involved in high level 'think tank' discussions in the board room.

Hearing loss is a very important social problem because the majority of people in our society will experience it at some time in their lives. Today as many as 7.5 million

adults in the UK have a hearing impairment whose average loss exceeds 25 decibels. At least three quarters of this group are over the age of 60. With this in mind, it is important to examine the projected rate of growth of the elderly. For the year 2001, it has been estimated that 25% of the population will be over 65 and 12% will be aged over 75.[1] Although old age is the leading aetiological factor in hearing impairment, NHIL (noise induced hearing loss) has been dramatically increasing. By the year 2015, the National Acoustics Laboratory of Australia predicts that 78% of men and 25% of women will be hearing impaired as a result of noise exposure.[2]

Indeed this same article in "The Lancet" goes so far as to suggest that hearing impairment, like failing eyesight, will in time reach epidemic proportions. This indicates that it is becoming increasingly important to study the ways in which hearing impairment makes its impact on intimate relationships.

The literature suggests that how to study the impact of hearing loss on relationships has continually baffled researchers. Much of the research to date has obscured many of the complexities involved in living with a hearing loss. The researcher's experience of profound hearing loss has suggested the considerable degree of complexity involved, particularly in the context of carrying out the roles of wife and mother. Furthermore, experiences as a social worker and counsellor suggested that the complexities in question might be more fruitfully explored and understood by adopting the technique of intensive repetitive interviewing, and by the use of a double focus: acquired hearing loss and family life.

By juxtaposing these two topics and by using the serial interviewing technique, it is shown how the former pathological picture of hearing impaired people, so widespread in the literature, was more likely to be a reflection of methodologies rather than reality. The limitations and imperfections of many former studies in the field of acquired hearing loss have become clear. By incorporating insights into the multi-faceted ambiguous nature of hearing loss together with an understanding of the anthropological approach as exemplified in the work of Elizabeth Bott,[3] this study has succeeded in exposing many of the hidden shades of grey in the problem as well as revealing a much more positive side of hearing loss and family life which other studies

have not uncovered. It is hoped that hearing loss may never again be seen as a black or white issue of 'hearing' or 'not hearing'. The multi-faceted and ambiguous nature of hearing loss must be acknowledged and more adequate provision made for hearing impaired people.

In all these respects, this study has broken new ground as it has given a fuller more comprehensive shape to our understanding of the impact of hearing impairment on family life. The study could also be used as a model by other researchers especially in the use of 'the life cycle' approach to examine cross sections of family life where there is parental hearing loss. Although a limited approach in certain respects, it nevertheless provides a good framework for future qualitative family research into hearing impairment. A second theoretical construct which impinged on the entire study was an understanding of the systems perspective. People in this study were always viewed in context. The hearing loss was seen to belong to the couple, the family, and the social network. It was never seen as a problem belonging solely to the individual as prescribed by the pathological model.

Let us now look at some of the major strands and psychosocial insights which emerged from the study as a whole and how they lead to recommendations for hearing therapy, research, and social policy. In looking at the findings, we need to keep in mind that their relevance has expanded with the formal implementation of community care proposals. Families will increasingly become primary settings for the care of people with disabilities. An effort has been made here to assess the particular needs not only of the people with the disabilities, but also of the family sub-systems for example 'the couple' on the one hand, and 'the children' on the other.

1. THE COUPLE RELATIONSHIP: INTIMACY AND THE QUALITY FACTOR

The point has been made throughout that while 'deafness as a difference' can exacerbate marital difficulties, it is rarely if ever the sole cause of marital breakdown. Conversely, evidence indicates that a hearing loss can facilitate relationship development. This is because the various strategies required for comfortable conversation with a hearing impaired person, for example ETTA, and 'looking', and 'repeating', actually encourage the development of all relationships. Evidence for this has been found by Noller,[4] who has noted that husbands who look at their wives when in conversation with them are 'high adjustment' husbands in that they are more likely to want to understand rather than to control their wives.

Using Sternberg's[5] definition of intimacy as the emotional closeness component of a relationship, a related point is made that 'deafness as a difference' does not obstruct true intimacy, provided that both partners have genuine feelings of affection and regard for each other, and that more often than not, they are able to respond to each other's needs. With this foundation, couples can explore the various types of intimacy suggested by Professor Olson: emotional, social, intellectual, sexual, spiritual, and aesthetic.[6]

A third point about marriage which emerged from the study is what may be called 'the quality factor'. It was put most succinctly by Theo aged 84 when she said:

> "I'm glad that (I) did have patience (with my marriage to Will), because it was worth it, and I think today some people don't wait to see if somebody's worth it."

Certainly a kind of fortitude and an ability to accept and integrate what comes is part of the quality factor. Parker also acknowledged this point with reference to the couples in her research:

"The pre-existing quality of the marriage and indeed, the personalities of the individuals involved, may be crucial in understanding what happens to couples after the onset of disability. Most marriages seem to survive, but whether or not they do is also related to the extent to which the partners are able to negotiate adjustment in their changed lives." [7]

Lastly, the relationship and the partner needs to be revalued. This involves seeing the partner in the best possible light and acknowledging that not anyone could have done what they have done, and that, therefore, they are significant and special.

Not all the couples in this study were able to go through this process, and four marriage breakdowns did occur. It is significant that all four marriages broke down in Stage IV in the life cycle. This fact confirms the literature's assertion that family tensions are the highest at this stage in that a massive transition is taking place as the children gradually become more adult and the parents attempt to rediscover what it is like to be a true couple again. Because it is such a vulnerable time, the teaching of very specific listening and communication skills is recommended, if they have not been learnt earlier, as there is enormous scope for misunderstandings. The teaching of such skills could be incorporated into NHS provision or through RELATE education programmes.

From primarily adult difficulties, we move to a discussion of the impact of hearing impairment on children. The literature suggests that children generally are not sympathetic when their parents are hearing impaired. This study suggests that the situation is more variable.

2. MANAGEMENT OF HEARING IMPAIRMENT AND CHILDREN

A second major strand to emerge from the study was the importance of the response of children to one parent's hearing impairment. This was analysed using the family life cycle approach. The experience of the eleven couples interviewed suggested that hearing loss was easiest to manage when in fact there were no children as there was understandably less conflict between the ETTA factor (Effort, Time, Thought,

Attention) required for one partner and the needs of the children. Generally, ETTA appeared to be the easiest to manage during middle childhood, Stage III, at a time when there is the least disruption to the family system, and children are identifying strongly with their parents. ETTA becomes most difficult when children were either joining the family at birth or leaving it as young adults. For example, when children are born, there is a loss of 'the couple' as the system becomes a small family. Traditionally it is the husband and new father who is most likely to feel excluded. If he happens also to be deaf, his feelings of exclusion are likely to be exacerbated. As we have seen, family tensions tend also to be very high during Stage V, the Adolescent Stage.

It was observed that step grand parenting combined with hearing loss could cause extra difficulties. It is possible that the more recent bonding of step grandparents will make competition and insecurity a stronger feature of relationships between generations.

The question still remains how did the study families deviate from so called 'normal families' and what impact did the hearing impairment of one parent have on the children's lives?

It emerged that the hearing impairment of one parent, especially if it came as an unexpected crisis, could cause worry and/or resentment in their children. These negative feelings could be modified and even transformed by sensitive management of the children and the disability. Children could also be helped by being given continuing reassurance. This study suggested boys, eldest children, and children without siblings were in the most need of such reassurance because they appeared less able to illicit it naturally.

The main adjustment required of the children when communicating with their hearing impaired parents was to face them when speaking and to be 'lipreadable'. This sometimes meant that children had to first locate their parents in the house. Frustration was especially experienced when they found their parents behind locked doors, such as when they were in a bathroom or study, and had an added obstacle to overcome.

Arthur, an adult child of Deaf parents, was the only one in the study who mentioned having responsibilities on behalf of his parents specifically in communicating with impatient 'officials'. He made it clear that he had not found this role unduly troublesome. There were no examples in the study of small children taking on adult responsibilities prematurely, a situation which has worried service providers as children are sometimes at risk when both parents are substantially hearing impaired.

There was considerable variation found in parental disclosure about hearing loss. It appeared that if disclosure took place when the children were quite young (3-5 years of age), the parents tended to emphasise 'responsibility' in their child rearing practices. On the other hand, if disclosure occurred slightly later (6-12 years of age), the parents appeared to be emphasising a care free childhood. In looking more closely at parent/child rapport, some families, were sensitive to a 'readiness factor' for discussions to take place, while other parents seemed aware of the need to create an appropriately 'close atmosphere' for such confidences.

Where reassuring discussions were not encouraged, there were a number of examples in the study of latency-aged children who appeared to want to share their parent's hearing loss perhaps hoping that this identification would 'make things better'. One child faked a pure tones audiometric test and was actually given a hearing aid to wear; and another child, whose mother was traumatically deafened, appeared to isolate himself in his room in an apparent psychological simulation of deafness.

Through out the study, grandchildren were observed as being just as capable as children in learning about adjustments to hearing loss namely in making themselves lipreadable. The positive attitude of grandparents to both their grandchildren and their hearing loss facilitated this process.

3. COMMUNICATION STRATEGIES: LIPREADING AND DISCLOSURE

While researchers have examined the cognitive components of the communication strategy of lipreading, the psychosocial components of lipreading have long been neglected. Five psychosocial stress factors emerged in this study in connection with

lipreading. They were stress caused in encountering strangers, stress with unlipreadable children, stress for men generally who felt threatened or provoked by the intimacy required in the act of 'looking' in order to lipread, stress in being forced to change long established marital communication patterns, and stress due to the forced 'looking' required when marital intimacy was experienced as frightening because of past failed relationships.

The study's findings suggest that taking responsibility for lipreading is an exercise in patience and courage on the part of both the hearing and the hearing impaired partner. Although feelings of irritation, frustration, and fatigue may be experienced on occasion, the more positive feelings of affection, respect and connectedness tend to prevail if a positive unconscious emotional 'fit' existed before the hearing loss was acquired.

The communication strategy of 'disclosure' was also frequently used by study participants. It was used in a very discriminating manner rather than as a simplistic general policy of appropriate behaviour recommended by some professional rehabilitators. Some of the social factors which appeared to influence disclosure patterns were race, nationality, gender, religion, class, and cultural values. Psychological and emotional factors which influenced decision making about disclosure were parental training, role expectations, personality of the speaker and the listener, immediacy of diagnosis, and concern for others. Lastly, environmental factors were mentioned such as when and where the question of 'disclosure' arose.

Thus it emerged that disclosure decisions made by the people in this study were based upon the interaction of numerous social, psychological, emotional, and environmental factors. This meant that they were most comfortable with a selective, thoughtful, sometimes intuitive disclosure policy, in effect very similar to hearing people generally in the management of the private details of their lives.

4. EVOLVING CONCEPTIONS OF CARE AND ETTA

A fourth major strand concerned the specific nature of the 'care' provided for hearing impaired people by their partners, kin and friends. While it has been consistently maintained throughout this study that 'the help' which a hearing impaired partner receives from his hearing partner does not 'fit in' with traditional forms of caring, there are, nevertheless, connections with it, specifically in terms of the 'measurement' and 'cost' of care. For example, we have seen that the hearing partner may take on from time to time the roles of buffer, interpreter, mediator, prompter, advocate, monitor, and editor. These roles involved close proximity to hearing impaired people as found in 'tending' and 'psychological care'. However, unlike traditional 'tending' tasks, when the whole relationship of the couples in this study was viewed, the 'caring' that took place was reciprocal and mutual. In other words, relationships were interdependent because the care went both ways as illustrated in Charts 4 and 5. In this respect also this study departs from many earlier studies where the person being cared for has not been 'heard', although Barry[8] and others are attempting to fill this gap.

The concept of ETTA (Effort, Time, Thought, Attention) has been introduced to signify 'the cost' in energy of care given as well as received. Hearing impaired people need 'access' to general conversation. While some people and cultures are naturally expressive and have a 'high involvement' manner with others, people from more restrained courteous cultures must think carefully about the extra energy expended so that a 'verbal ramp' is offered to a hearing impaired person. Problems may arise in the latter cultures where a certain type of intimate, emotional and personal communication is simply not part of cultural norms, unless people happen to be helping professionals and have integrated their professional values into their personal life.

There were some unexpected gender shifts in this study. More men appeared to be involved in 'caring', not in a traditional 'tending' sense, but in helping the hearing impaired person to ward off isolation in one way or another. Nearly all were quite happy to take on the communication roles described, while some maintained more secondary roles as 'watch dog'.

The other interesting shift was found in the stories of Max and Theo in that it was the widower, Max, who was surrounded by his 'caring' family, while it was the widow, Theo, who had almost more autonomy than she could manage.

5. QUESTIONING SOME ASSUMPTIONS AND LABELS

a.) As in every discipline, the literature in the Deaf field holds to be true certain assumptions and labels until they are proven to be otherwise. The charts in Chapter XIV were developed in the hope that they would stimulate further thought about some of the medical/ audiological and social policy assumptions which prevail. These show that the people in this study experienced no correlation between the time of onset and the degree of deafness with overall adjustment, and that 'care' was a reciprocal affair between the hearing impaired partner and the hearing partner.

b.) The findings of the study also call into question certain assumptions about prelingually Deaf people specifically the case of Arthur. Although theoretically his needs should have been different from the other people in the study with acquired hearing loss, his excellent command of spoken English as well as his use of BSL meant that his communication potential was equal to if not better than other hearing impaired people in the study. This suggests that 'labels' in the Deaf field must be used with extreme care to ensure that they do justice to the complexities of the lives of individual Deaf people.

c.) Up until this time most of the literature in the Deaf field has focused on how the experience of acquired deafness impovishes the environment of hearing impaired people in comparison with people who hear. This study seeks to show that although some deprivation does occur, nearly all of it can be compensated for by the acquisition of a psychologically healthy state of being for a hearing impaired person, by an informed and compassionate spouse, and by an informed and appropriately caring social network. This therefore suggests that the challenge for hearing people is to keep in mind that those with hearing loss are the same and different from themselves.

d.) Lastly, there are considerable discussions in the literature regarding the medical/individual model verses the social model of disability. This study draws from each model when appropriate and so depicts a fuller account of realities.

6. REHABILITATION WORTH

Another developing strand in the thesis was that hearing impaired people in the UK have not been given sufficient and/or appropriate guidance at the time they are diagnosed to help them cope with the multi-faceted ambiguous nature of acquired deafness which penetrates into the heart of all their intimate and social relationships. There appears to be three reasons for this connected with the individual, his social network, and societal norms generally.

Firstly, people who acquire a hearing impairment carry within them the negative attitudes their socialisation has taught them about deafness. Regardless of age, people still experience losing their hearing as an unexpected crisis, and it precipitates strong negative feelings, and sense of being noticed as different and stigmatised. As we have seen, these negative feelings lower self esteem and confidence. This suggests that hearing impaired people themselves find it immensely difficult to make their needs known even if they are fortunate enough to understand their complexity and ambiguity and see themselves as credible friends. In this respect, hearing loss is an individual problem.

Secondly, this study indicates that kin, friends, and professionals who compose the social support network of the person with acquired hearing loss, are in fact in a very powerful position. This is because these people psychosocially construct the hearing impaired person's 'rehabilitation worth'.

Unfortunately, as we have seen, network members may often collude with the negativity already experienced by the person with acquired hearing loss rather than fight against this attitude, and a vicious circle is created resulting in the 'deafness as acquired oppression' described by Woolley,[9] Kyle,[10] and McKnight.[11]

Informal or formal care managers often do not recognise the needs of people with acquired hearing loss because they are not expressed. There is often a defective assessment of needs even when they are assessed since most care managers are only aware of one or two aspects of the problem. When services are delivered through defective assessment, the same ignorance of the problem bedevils the relationship again, but on a lower level in the health care hierarchy. An example of this was Frank whose wish to be informed about his hearing loss was thwarted by the technicians who fitted his hearing aid because giving out such information at that level was against NHS policy.

Carers are also likely to discover that unless they understand the specific special needs of people with hearing loss and the greater possibility of communication breakdown, they are unlikely to obtain the full cooperation of people with hearing loss in their more general care.

Lastly, rather than being helpful, there are certain norms[12] found in certain cultures which work directly against the needs of hearing impaired people. A more general traditional norm in this instance is that people should live with their problems as best they can rather than seek help for understanding the multi-faceted nature of acquired hearing loss.

7. SOCIAL NET WORKS AND HEARING IMPAIRMENT

Although hearing impairment is often connected in the literature and in the imagination with isolation, it emerged that the majority of the study participants were not isolated. This was because most of them had learned, with the help of their partners, how to overcome the communication barriers and develop friendships in various ways. These will now be discussed.

a) A number of people in the study, both hearing and hearing impaired partners, took a proactive approach in establishing their social network. From the beginning they sought to take charge of 'stigma management' in various ways. As we have seen, although Joy was unaware of any particular strategy, she did in fact follow one which

included the following tactics: 1) She returned to live in the town where she grew up. This helped her to reestablish herself with old friends and formed the base of her network; 2) She quickly affirmed that she was the same person despite her deafness and had not lost her social skills; 3) She found that people could learn quickly how to speak to her by watching how her husband, Mike, operated; 4) Doing things socially in couples and groups meant that ETTA and interpreting roles could be shared so that Mike could have a break if he wanted one; 5) They also belonged to a self help group.

b) In examining the couples, it emerged strongly that those who were the best adjusted, all belonged to self-help groups of varying natures. Those represented were Croydon Hard of Hearing Group, the Break Through Trust, the Royal National Institute for the Deaf, LINK, Nigerian doctors in Britain, and the National Association of Deafened People (NADP). Each group had a different focus and provided different types of support, but there was the common similarity in that people with hearing impairments were accepted. Such groups were especially helpful for recently deafened people, or people who had experienced some other major transition such as a move or migration.

c) For some people, their own family could make a most appropriate support or self-help group. The findings suggested that most families tried to provide support for their hearing impaired relations, but that they were continually bedeviled in this task because of the ambiguities involved. The best illustration of this was the widowed grandfather, Max. Although he longed to take part in conversation at the dinner table with his daughter's family, this was often difficult to do because of the conversational style which they adopted. Specifically, in Max's family, feelings of 'belonging' were generated by unstated meanings and being privy to the mundane details of everyday domestic life. When a hearing loss prevented their absorption by Max, the situation became more complex because of traditional English dislike of repeating so called 'trivia'.

Although such norms and habits are extremely difficult to change, awareness training programmes, for example in the need for ETTA, could be channelled through local RELATE organisations so that families might better understand the multi-faceted and

ambiguous nature of hearing loss. There is also need for a revisioning of the two major communicating strategies required, 'repeating' and 'looking', so that they may be seen as an enhancement to conversation rather than an obligation.

d) All the people in the study had contact with professionals who were also part of their social networks. Teachers and social workers were seen to be the least helpful as they were connected with past oppression and disapproval of BSL. Doctors were seen as helpful especially if they understood their value to their hearing impaired patients despite the fact that they could not cure them. Clergymen were generally seen as helpful facilitators.

Very few of the study participants had actually met a hearing therapist which is not surprising considering the small numbers that have been trained. A way forward here will be discussed in the next section.

8. RECOMMENDATIONS FOR SOCIAL POLICY

It is obvious that there is no one solution for helping people with acquired hearing loss become more integrated within their families and within society. However, some recommendations may be made. Firstly, a multi-disciplinary holistic approach must be adopted when working with hearing impaired people because of the multifaceted nature of the problem. This may be done partly by upgrading the training of hearing therapists so that they receive a more rigorous foundation in the theoretical aspects of their profession away from the medical model towards a deeper understanding of the systems perspective and psychosocial aspects of hearing loss.

Other professionals working with people with acquired hearing loss must put rivalry aside and insist on greater cooperation across the services of education, the national health service and social services. Ideally an institute should be established where a multi-disciplinary holistic approach could be employed and counselling, training, and research into acquired hearing loss take place. Such developments would be in line with the original recommendations made to the DHSS by their subcommittee, ACSHIP,[13] which were unfortunately so neglected when hearing therapy was

established in 1978. Much also may be learned from the experiences of Sweden, Germany, Denmark, and the USA.

Such developments need not wait for the actions of politicians. Hearing impaired people themselves have a crucial role to play in helping to change ideas, services, and policies in ways which suit them.

In other words due to the importance of developing a group identity to create a platform at local and national levels, it would be of enormous benefit if self help groups could be established run by executive committees composed of hearing impaired people with the support of hearing people. This would help hearing impaired people in a number of areas. Firstly, they would find support and understanding by interacting with other hearing impaired people. Secondly, their sense of' 'rehabilitation worth' would arise as they became more accepting and knowledgeable about hearing impairment. Thirdly, with acceptance and knowledge comes responsibility and hopefully the capacity to communicate to others the complex nature of hearing loss. Fourthly, awareness and training programmes need to be introduced so that families may learn how to transform aspects of their attitudes and domestic culture which cause their hearing impaired members particular frustration. Rocky Stone, the founder of SHHH (Self Help for Hearing Impaired People) in the USA had this to say about the benefits of a self help approach.

> "Most of us recognize that human understanding is possible only as long as channels of communication are kept open. Unless we can communicate with our neighbour we have little chance of understanding him, or vice versa. When there is a break down in communications process, such as loss of hearing in one of the participants, not only good will but knowledge becomes important. We have to find new ways to communicate. We have to do this while retaining confidence that the human spirit is stronger than anything that can happen to it. We have only lost our hearing...not our humanness."

" Once we get this into perspective, we can generate the courage too go on. And we go with others. We are engaged in 'Self Help'. We are pulling together...all crew, no passengers. And though the race be difficult, we feel better already"

Thousands of hard of hearing people throughout the USA, in Canada and Australia, have made a decision about themselves. They are learning, growing, asserting...they are Self Help in Action.[14]

9. RECOMMENDATIONS FOR FURTHER RESEARCH

With regard to future research, there is much to be done. On a general level, more research needs to focus on families and how they respond to a family member who has a sensory loss such as hearing impairment as there are so many ambiguities involved, and because communication is so central an issue in family life. This could be done by building on the framework established in this study using the Family Life Cycle although the family life course could also be used.

Most of the couples in this study were middle class and well educated. A study along similar lines, but where there is more deprivation, is recommended. We need to know more about what happens in families who experience financial deprivation.

More substantial research on lipreading is needed to tease out the impact of various social factors such as culture, gender, ethnicity, personality, personal history, and feelings about the person speaking.

Another area which this study suggests is that of more research into the lives of the elderly and their friendships as nearly 50% are hearing impaired and many appear to suffer because of this.

The paradox seems to be that when one discovers answers for understanding distinctive relationships, the same knowledge may be applied for all couple/family relationships in that it is impossible to live together with out confronting 'differences' whether it is gender, personality, nationality or hearing loss.

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APPENDIX 1

PROFILES OF THE STUDY'S 11 COUPLES AND 5 INDIVIDUALS

Joy (HI) and Mike (H)

Joy (60) and Mike (60) have been married 30 years. Mike works for a printing firm. Before Joy was deafened, they ran a business together and their attitudes were aspiring. Joy was deafened 17 years ago from meningitis. Although initially a highly trained secretary, she eventually found a job as a dinner lady in a primary school cafeteria. They have one son, James now 30, who was recently married. Joy was an early cochlear implantee. She lipreads and is presently taking BSL. This couple represented Stage VI or the Middle Years in the Family Life Cycle.

Julia (H) and Sam (HI)

Sam (41) was deafened from drug toxicity at 18 years of age. He was, nevertheless, able to complete his BS in mineral sciences at Leeds University where he met Julia (33). Sam is a computer programmer for an insurance company and Julia co - directs a textile business. They have no children and have been living together for ten years. Sam wears no hearing aid and relies on lipreading and his partner's interpretation. He knows BSL and some finger spelling, having taught briefly at Doncaster School for the Deaf. This couple represented partners without children or Stage I in the Family Life Cycle.

Barbara (HI) and Ben (H)

Barbara (45) was severely impaired resulting from her mother's rubella. She met Ben (39) after both had qualified in the legal profession and they have been married ten years. While Ben has continued with his career, Barbara dropped out to give birth to their two children. Louise (10) and Jonathan (9) were also interviewed. Barbara has since become

an administrator in a national Deaf charity. Barbara is an excellent lipreader and wears both a behind the ear aid as well as a box aid on occasion. This family represented Stage III in the Family Life Cycle.

Sarah (H) and Joe (HI)

Sarah (47) and Joe (63) have been married for seven years. Both have children and grandchildren from former marriages. Sarah has a daughter and two grandsons. Joe has two sons who were estranged, but have recently become reunited with him. Joe lost much of his hearing as a baby from diphtheria. Today he has a severe loss, wears two hearing aids and is an excellent lipreader. He has his own design business. Sarah is employed as a lipreading teacher by the local authority. They represent Stage VI or the Middle Years of the Family Life Cycle.

Kay (H) and Henry (HI)

Kay (41) and Henry (39) have been married for just over six years. Henry has a severe hearing loss resulting from his mother's rubella. He wears two hearing aids and is an excellent lipreader. They represented Stage II in the Family Life Cycle as they have two children, Clive (4) and Christy (1). At the time of the interviews, Kay, an experienced teacher, and Henry were finishing up their training for the ordained ministry and were looking forward to leaving school and serving their title in their first parish. Henry had recently completely Stage-I in BSL.

Gwen (H) and Arthur (HI)

Gwen (27) and Arthur (25) were also in Stage I and the real newly weds in the study in that they had been married for just over one year when interviews began. Arthur has a profound hearing loss and grew up as a member of a Deaf family. He wears two hearing aids, lipreads, and Signs fluently. Gwen worked as a primary school teacher and gave birth

to a son during the interview period. Consequently, Arthur had decided to give up his studies and was about to take up a civil service position.

Anne (HI) and Adam (H)

Anne (38) and Adam (42) have been married for 18 years. They represented Stage III and IV in the Family Life Cycle as their children, Jane and Rupert were 11 and 13 years of age respectively. Anne had very recently been diagnosed as having a mild/moderate senorineural bilateral hearing loss. She did not wear an aid nor did she lipread. She worked as a social researcher while Adam was the head of the business development division in a college of higher education.

Simone (H) and Frank (HI)

Simone (63) and Frank (64) had been married for 39 years and also represented Stage VI in the Family Life Cycle. Eight years earlier, Frank had been diagnosed as having a mild/moderate sensorineural bilateral hearing loss. He varied in wearing one, sometimes two hearing aids, but does not lipread. Simone who is French, had recently retired as the head of the French department of a secondary school. At the time of the interviews, Frank was nearing his retirement as a Professor of History and Administrator in a London University. They had two adult children, five grandchildren, as well as Simone's elderly parents to look after during the holiday periods in Provence.

Anthony (HI) and Clare (H)

Anthony (37) and Clare (30) have been married for ten years and have three school aged children . They were in Stage III of the Family Life Cycle. Anthony and Clare are Nigerian. They came to the UK for Anthony to be rehabilitated after he was deafened

from drugs given to save his life when complications arose during an appendectomy operation. He was eventually able to retrain as a pathologist while Clare worked as a letting officer for the local council. Anthony and Clare are the one couple in the study who attended the Link Centre, the British Centre for Deafened People in Eastbourne. Anthony wears a hearing aid with a masker because of his tinnitus. Although he was offered a cochlear implant, he refused. He lipreads very well.

Mary (H) and Robert (HI)

Mary (68) and Robert (71) were retired teachers with four adult children and six grandchildren. They represented Stage VII in the Family Life Cycle. Robert had contracted Meniere's Disease just before he retired. At the same time, the family experienced two other crises: Mary and Robert had a Downs' Syndrome grandchild and their youngest son had a schizophrenic breakdown. Robert coped by becoming proficient in the use of a radio microphone although he continued to suffer from vertigo. Mary trained late in life to be a music teacher for special needs' children. She has taken early retirement so as to be more available to her family.

Rachel (H) and Richard (HI)

Rachel (46) and Richard (50) had been married for 23 years. They have two sons, John and William, who were in the process of leaving home. Consequently, this family represented Stage V in the Family Life Cycle. Rachel had contracted otosclerosis when she was 26, a condition inherited from her father. She wears two hearing aids, and has been operated upon for her condition. She does not lipread. Richard is a management consultant and Rachel is a sociology lecturer.

Grace (HI)

Sue (70) is single and divorced, having previously been married to her husband for 22

years. She maintained a business partnership with him which involved her as the decorator in the conversions of old flats. She had gradually acquired her profound hearing loss which had been inherited from her mother. She is active in Deaf advocacy work, but has no children.

Christine (HI)

Christine (70) is also single and divorced. Her former husband, a doctor, left her for another woman, contracted hepatitis, and eventually died. Christine now has three sons and 8 grandchildren who she sees regularly. Christine was gradually deafened, a condition thought to be caused by pneumonia in childhood. She has a cochlear implant, lipreads and uses sign language (ASL). At 50 she retrained as a rehabilitation counsellor and researcher. She has retired from counselling, but continues to do research.

Martha (HI)

Martha (55) is a single mother and has two adult children. She blames her severe hearing loss on scarlet fever which she had as a child. She lives with her son, a niece, and a dog. The father of her children left her many years ago and she is presently on social security. She wears one hearing aid with difficulty. She suffers from periods of depression.

Theo (HI)

Theo (84) has been a widow for the last three years. Before her retirement at 71, she was the headmistress of a private primary school. She has one son and three grandchildren. She has a mild/moderate hearing loss, and wears one hearing aid. She has never been to a hospital to be properly tested.

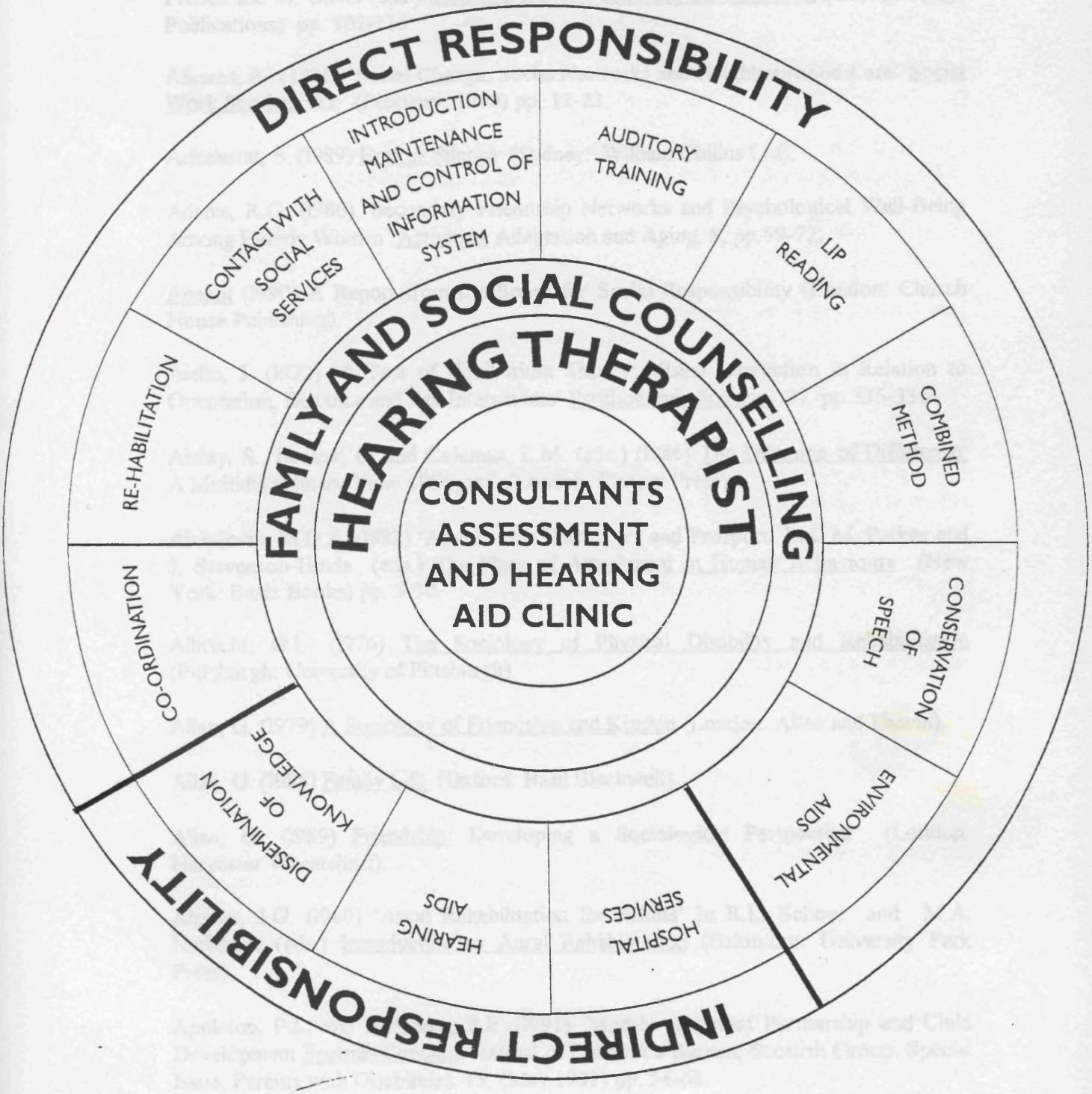
Max (HI)

Max (81) has been a widower for the last seven years. He has two adult daughters and seven grandchildren. He was formerly the headmaster of a large comprehensive secondary school in Croydon and was once the chair person of the National Union of Teachers. He has a mild/moderate hearing loss and wears one hearing aid.

All of people in the study lived in London with the exception of Gwen and Arthur who lived in Southampton.

APPENDIX II

THE DIRECT AND INDIRECT RESPONSIBILITIES OF THE HEARING THERAPIST



Taken from the Appendix of the report made by the subcommittee of the Department of Health and Social Security's Advisory Committee on Service's for Hearing Impaired People. (September, 1975).

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