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FOCUS ON FATHERS:
A PHENOMENOLOGICAL STUDY OF THE EXPERIENCES OF FATHERS OF HEARING IMPAIRED CHILDREN

BY
MARGARET KAY

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
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IN
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DEPARTMENT OF EDUCATIONAL PSYCHOLOGY
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Focus on Fathers: A Phenomenological Study of the Experiences of Fathers of Hearing Impaired Children" submitted by Margaret Kay in Patial fulfillment of the requirements for the degree of Master of Education in Special Education (Hearing Impaired).

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ABSTRACT

The purpose of this study was to listen to the experiences of hearing fathers with hearing impaired children. Five couples, mothers and fathers of hearing impaired children, were interviewed. Following transcription of the tape recorded interviews phenomenological data analysis took place based on a technique described by Colaizzi (1978). The transcribed interviews were reduced to significant statements. The plethora of material at this stage was too great for the scope of this study and only the experiences of three of the fathers were included in the subsequent phenomenological analysis . However, the experiences of the coresearchers which were not included in the actual analysis all served to support those of the three ultimate coresearchers.

Phenomenological analysis of the transcribed interviews revealed themes which characterized the experiences of the fathers. Common themes were clustered into higher order thematic descriptions. These themes included 1) fear, 2) frustration, 3) trauma, 4) conflict, 5) retrospective learning and 6) involvement. A higher abstraction of these clustered common themes reflected two second order themes. These were 1) the encounter with a new and unexpected experience and 2) that integration of new experience leads to personal growth and increased acceptance of a child's deafness.

The study indicates a need for greater awareness of the ways in which medical and educational services are disseminated to the families of hearing impaired children and the affect that personnel in those disciplines may have on the dynamics of such families. Inclusion of fathers when such services are provided could help alleviate some of the stress experienced by the fathers and their families.

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I wish to express my deep appreciation to the families of hearing impaired children who gave so generously of their time, their privacy and their concern. Without them this study could not have been done. Working and sharing with them was an honor and a learning experience for me.

Without the gentle encouragement and scholarly guidance of Dr. John Osborne this study would not have come to fruition. He was a "long-distance" mentor who always assisted me when I was ready to quit. I owe him my sincere thanks.

To my family, who have had to bear the stresses and strains of a wife and mother who was often trying to juggle too many balls, I offer my thanks and apologies for the time which this study has taken away from our time together.

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CHAPTER I

INTRODUCTION

Personal Perspective

As the hearing mother of a hearing impaired son who is now a young man of twenty, I have always been struck by the similarities between the experiences of my family and those of other parents with a hearing impaired child. Reading autobiographical accounts written by such parents, or talking and working with them, frequently reveals shared experiences or different aspects of a similar event. Each contribute to my understanding of hearing impairment and how it affects the hearing family with a hearing impaired child.

However, such empathy and understanding are not always evident when I read medical, psychological, and educational texts. Books, papers, and journal articles, especially those which are based on natural scientific research, often appear to be removed from my experience and to have a patronizing quality when discussing the effect of hearing impairment on families. This may, in part, be because natural science methodology seeks to quantify aspects of the person or people being researched rather than seek meaning from their lived experiences. The actuality of lived human experience has been eliminated from the "scientific method" (Colaizzi, 1978). Phenomenological research seeks the meaning of experience which has been collectively created over time and which transcends the experience of any one individual (Salner, 1986).

My reason for choosing this study was to augment the limited existing data about families of hearing impaired children and to increase our understanding of their experience. Parents have to make decisions for their hearing impaired children before they have had time or opportunity to understand all the complexities of the situation. Increased knowledge about the experiences of hearing families with hearing impaired children should allow those families to cope with stresses and to make decisions for their young children that allow those children to reach their full potential. This increased knowledge may also lead to a greater understanding of both hearing and deaf culture.

It is important for those working with hearing impaired children to recognize dynamics working within the family system which may affect the child. Factors which may influence the family with a hearing impaired child include such things as the degree of hearing impairment, age of onset, age of diagnosis, the hearing status of the parents, awareness of communication methods, understanding of the social and linguistic needs of the child, and the degree of support and information available to the family.

As a professional working with parents of hearing impaired children I often fall into the trap of providing information and advice rather than listening to a family. When I do have the opportunity to listen it is usually to mothers. Fathers attend meetings and come to school less often than mothers and are usually at work if a home visit is made during working hours. As a result they are often excluded from appointments and meetings which involve their children.

Until now research has focused mainly on other handicapping conditions and generally on mothers or on a generic entity called "parents". Fathers have seldom been identified for special study. Increased knowledge about the fathers of hearing impaired children may facilitate the provision of more effective support for their families.

Matching Method to the Study: Why a Phenomenological Approach?

The diverse nature of hearing impairment (mild to profound, pre or post-lingual, conductive, or sensory neural) combined with the mode of communication, differing socio-economic levels, educational abilities, and family circumstances of the people involved , make many aspects of hearing impairment difficult or impossible to quantify. This diversity is especially relevant when looking at the ways in which hearing impaired children and their families interact with professionals in the fields of medicine and education. It is difficult to generalize from specific studies in the field to other hearing impaired children. There are always disclaimers to be added such as: "But those children only had moderate losses", or "If only we had those ideal circumstances...". No one method is correct for conducting all research (Polkinghorne, 1983, as cited in Salner, 1986). The question to be answered should determine the choice of method. However, human science methods, which look for meaning of the phenomenon being examined, and draw their data from the human experience, seem ideally suited to this study.

Phenomenological research methods attempt to understand the lifeworlds of people (Becker, 1986), rather than develop causal theories. Interviewing and recording the responses of parents who share the experience of having a hearing impaired child allows for the identification of recurrent themes and experiential structures. Because of the disparate nature of the experiences of the fathers I sought to understand their experience by looking for common structures. This empathetic understanding, the identification of common structures between the experiences of different coresearchers, and the ability of a reader with similar experience to relate to the results of the analysis, constitute validity in a phenomenological study. Generalizability will be established a posteriori (Osborne, 1990).

Being the parent of a hearing impaired child, albeit a mother and not a father, as well as a professional working with hearing impaired children and their families, gives me a history of experience with the topic being investigated. Existential-phenomenological research methodology recognizes my presence and allows me to "articulate any predispositions and biases through a process of rigorous self-reflection so that those who read ... the research will be able to take the frame of reference into account" (Osborne, 1990). The stating of my preconceptions and assumptions or bracketing is detailed later in this study.

A further advantage of the phenomenological method is that the use of descriptive narrative as an integral part of the analysis of the data allows the reader to become involved. The described experiences of the coresearchers and the identification of recurrent structures in their descriptions may trigger memories or allow insight into previous experiences for people who read the final report (Van Manen, 1984).

The following list of terms used in this study is provided for the purpose of clarification and information of those readers who are unfamiliar with deaf and phenomenological terminology.

Definition of Terms:

American Sign Language

A form of manual communication used in North America which constitutes a distinct language system.

Bracketing

Reflection by the researcher in order to recognize, acknowledge and set aside biases and preconceptions about the phenomena so that structural components through which the experience is formed may be revealed (Becker, 1986; Polkinghorne, 1981). "...the phenomenological researcher attempts to articulate predispositions and biases through a process of rigorous self-reflection so that those who read reports of the research will be able to take a frame of reference of the researcher into account..." (Osborne, 1990).

Conductive Hearing Loss

Loss of sensitivity to sound due to abnormalities of the middle and/or outer ear (Martin, 1986).

Coresearchers

Participants in the project who shared their experiences with the researcher in order to explore the phenomena being studied. In this study they were fathers and mothers of hearing impaired children.

Deaf

A person with a hearing impairment (usually 70dB or greater) which precludes the understanding of speech through the ear alone, with or without the use of a hearing aid (Moores, 1982).

Hearing Impairment

Loss of hearing severe enough to cause communication disorders requiring remedial and educational treatment (Rodda, 1987).

Moderate Hearing Loss

A hearing loss of between 41-65 dB pure tone average at 500, 1000, and 2000 Hz (Martin, 1986).

Oral Communication

The use of speech and lip reading for the purpose of communication.

Phenomena

Conscious experience

Phenomenological Research

A methodology based on the philosophy of Edmund Husserl (Osborne, 1990). "Phenomenological research seeks to develop presuppositionless, structural descriptions of what is given in experience. It uses specific methods designed to direct attention to what is given in human experience, to free the researcher from prejudgments about the data, and to bring to view the structural components through which experience is formed" (Polkinghorne, 1981).

Phenomenology

"The study of the structure and the variations of the structure, of the consciousness to which any thing, event, or person appears" (Giorgi, 1975).

Profound Hearing Loss

A hearing loss greater than 96dB pure tone average at 500, 1000, and 2000 Hz (Martin, 1986).

Sensorineural hearing loss

Loss of sensitivity to sound due to abnormalities of the inner ear and/or nerve pathways between the inner ear and the brain (Martin, 1986).

Severe Hearing Loss

A hearing loss of between 66-95 dB pure tone average at 500, 1000, and 2000 Hz (Martin, 1986).

Sign Language

The use of manual signs to encode language.

Signed English

A manually coded representation of spoken english.

Total Communication

The simultaneous use of speech and a manual representation of english syntax.

<u>Human Science</u> and
<u>Natural Science</u>
These terms are explained in detail in Chapter III.

CHAPTER II

LITERATURE REVIEW

Information in the literature pertaining to hearing impairment contains little which is specific to fathers of hearing impaired children. For that reason this review looks at information on hearing impairment as it affects families as a whole, rather than just fathers. A diversity of studies from both natural and human science literature have been studied. Because personal experience is seminal to this study, individual accounts which have not been written using a strict scientific method have also been included. For the purpose of organization and ease of reading the review has been organized into four categories. These are family dynamics, stress, early diagnosis and early intervention.

Introduction

The majority of studies about hearing impairment fall within the natural science mainstream. Data gathered using this method of scientific research has been used to investigate a wide variety of topics from the area of childhood hearing impairment such as reading (LaSasso, 1987; Maxwell,1986), oral versus total communication methods (Arnold, 1984; Nix, 1981), the effect of differing levels of hearing loss on language, educational, psychosocial behavior of children (Davis, Elfenbein, Schum & Bentler, 1986), and teaching and learning styles (Wood, Wood, Griffiths & Howarth, 1986). Although these studies do not directly relate to the focus of this research, it is important to acknowledge their existence. They form the base for much of the information that is disseminated to parents, especially when the hearing impairment is newly diagnosed or when parents are faced with a new situation such as starting their child in school.

Individual accounts of living with hearing impairment are often written from a clearly defined perspective. For example, the deaf culture (Jacobs, 1980), raising a child in the oral tradition (Stern, 1987), or in a single-parent family (Robinson, 1979).

The diversity of these studies emphasises the far-reaching effect that hearing impairment has on both hearing impaired children, and in families. Both the diversity and the amount of the information can be overwhelming for parents and may be more confusing than helpful to parents trying to understand their child's situation while at the same time faced with making choices that will affect the future of both children and families.

The use of a team approach in delivering service to families with a hearing impaired child is advocated by Swick (1987). The multifaceted nature of family needs would be effectively served by professionals from different disciplines working together, utilizing each others skills and talents. For example, doctors, both family practicioners and specialists, working closely together with other disciplines such as, audiology, speech language pathology, early intervention programs, social work agencies, and educators could provide a unified service to the family of a hearing impaired child. The advantages are numerous; the number of appointments and meetings which families are expected to attend may be reduced, the amount of material which those families are asked to absorb may also be reduced. All the information which is given to parents would come from a unified source allowing professionals to look at the children within the framework of their families. Such an interdisciplinary approach to service could negate the enforcing of "absolute standards or goals" (Murphy, 1979) by professionals who adhere to different ideologies and methods. It would allow for a balanced approach to the needs of both the families and their hearing impaired children.

Family Dynamics

Families need accurate information in order to be prepared for the challenge of parenting a hearing impaired child (Atkins, 1987). Not only information pertaining to hearing impairment but also support to alleviate the increased stress which is experienced in families of hearing impaired children. Programs are needed for the whole family. Each family member may be affected by living with a hearing impaired sibling or child in a different way and at a different time. Further, every family is unique and has "individual needs that require individual solutions" (Gallagher, Beckman & Cross, 1983).

Studies call for more understanding of the family and acknowledgement of its importance (Atkins, 1987; Gallagher, Beckman & Cross, 1983; Kampfe, 1989; Luterman, 1987; Seligman, 1985). These studies emphasize demographic characteristics of all families e.g. socioeconomic status, interpersonal supports, extended family and friends, which take on increased importance in families with handicapped children. "The greatest impact of deafness is upon the family unit and the relationships of its members" (Morgan, 1987, p.48). In order to fully understand the ramifications of hearing impairment we need to know more about the societal context in which that child lives. The family is the intermediary between an individual and society (Murphy, 1979). Gallagher, Beckman and Cross (1983), advocate understanding of various patterns of family interaction inorder to give help and direction to family service programs.

There is a dearth of literature pertaining specifically to families with a hearing impaired child and the dynamics which occur within that unit (Luterman, 1987). Authors writing in this field are easily identified and their work is familiar to those who work with the hearing impaired (Gregory, 1976; Luterman, 1979, 1984, 1987). Much of the writing is in books, either drawing together the work of previous research on various aspects of hearing impairment and directed at parents for use as an information source (Freeman, Carbin & Boese,1981), or written by family members as a biographical account of their individual experience with their hearing impaired children (Bloom, 1963; Forecki, 1985; Spradley & Spradley, 1978; West, 1970). Though these biographical accounts are not written as a medical or educational treatise, they are personal accounts which tell much about the lived experiences of those families.

Bloom (1963) writes as the mother of a daughter with a profound hearing impairment. Her book is an attempt to pass on to other parents of hearing impaired children much of the material which she gathered as her own child was growing up and learning to speak. Her common sense approach and practical analysis of the ways in which parents interact with their children is still informative and relevant thirty years later.

In contrast, is the story of a family who struggled with their daughter's slow and frustrating attempts to communicate with speech and their eventual break from their advisors to discover communication through sign language. (Spradley & Spradley, 1978).

Quite different again is the work of West (1970), who writes of his deaf daughter and their relationship as a powerful celebration of her differences and the changed ways in which she makes him look at the world. It is a piece of writing very different from scientific documents. Yet because it is filled with the writers discovery, through his daughter, of a whole new world, it has much to add to our knowledge of the dynamics that occur within families and their hearing impaired children.

Two monographs provide a collection of articles relating to families with hearing impaired children included in which are personal narratives (Atkins, 1987; Murphy, 1979). One of these articles is the transcription of an interview with the hearing impaired parents of two hearing impaired children (Thompson, Thompson & Murphy, 1979). The article is informative in that it tells of the lived experiences of the parents. The reader is given insight into the parent's struggle with the diagnoses of deafness for their children and their subsequent realization that they have never fully accepted their own deafness. However, there is no analysis to illuminate the meaning of that experience.

In the same way, autobiographical accounts (Bloom, 1963; Forecki, 1985; Spradley & Spradley, 1978; West, 1972) allow us insight into the life of the family but do not seek the underlying meaning of that experience. This is unfortunate because these books, especially that written by West (1972), are written with much introspection and contain a plethora of material which sheds light on the lived family experience. The struggles with diagnosis, experiences with finding, deciding upon and learning a method of communication, interactions with family, professionals and peers are all experiences which affect these families in different ways. These accounts are valuable because they serve to situate the hearing impaired child within the family unit rather than isolate certain behaviors or attributes.

Gregory (1976) in a large study of 122 mothers of hearing impaired children drew upon their personal experiences. Her book organized direct quotations from the mothers to illustrate various topics, including problems with initial diagnosis, the needs of deaf children, communication difficulties, family life with a deaf child and the changes that such children make within the family. The quotations were connected by simple narrative. Nowhere did the book seek to advise others or to tell parents what should be done to help their hearing impaired children. It very simply "painted a picture" (Gregory, 1976, p. 17) for the reader of family life with a deaf child from the perspective of the interviewed mothers.

Stein and Jabaley (1981) urged the establishment of good parent-child relationships in order to avert many of the emotional and behavioral difficulties which beset deaf adults. Greenberg (1980) listed problems frequently encountered by hearing impaired children and their families.

Hearing parents were reported to have inappropriate attitudes toward their deaf children ranging from overprotectiveness to (or simultaneous with) overindulgence. Deaf children have been repeatedly characterized as low in social maturity and self concept (Di Carlo & Dolphin, 1952), and as impulsive, immature, and egocentric (Garrison & Tesch, 1978).

A recent human science research project which did provide an analysis of lived experience was a phenomenological study by Morgan (1987). She interviewed five mothers of hearing impaired adolescents. She found

wives' suffering and own sadness, they may be less aware that their own self-esteem has suffered.

A deaf child's handicap threatens the integrity of marriage in different ways (Featherstone, 1980). It reshapes the way in which the family is organized, acts as a symbol of shared failure, creates the possibility of conflict and excites strong emotions. However, because of the different roles which mothers and fathers play within the family structure it is reasonable to assume that fathers of hearing impaired children may have different experiences and emotions from mothers.

Stress

The families of hearing impaired children experience an increased level of stress (Luterman, 1987). Parental reaction to a child's hearing impairment varies from parent to parent and between families. This depends partly on previous experiences. For parents who have never had to cope with a crisis in their lives the birth of a deaf child can be their first brush with adversity. Parental reaction also depends on the ability of each individual to cope with the stress. Various models of grieving and acceptance have been used to explain the process through which parents of a hearing impaired child must go. The stages of (1) denial, (2) anger, (3) bargaining, (4) depression, and (5) acceptance , as identified by Kubler-Ross (1969) are frequently used.

However, such linear models may be too simplistic for a complex process. For parents of a hearing impaired child these stages are not mutually exclusive and there is no clear demarcation between them. Luterman (1987) lists parental feelings of shock, anxiety, anger, depression, guilt, resentment, vulnerability, overprotection, confusion, panic, and denial as reactions to crisis. "The crisis is not in the event but in the response to the event" (Luterman, 1987, p.48). Any one or more of these feelings can occur or recur as changes or "events" occur in the life of a hearing impaired child. The sequence may vary; some may miss stages, and those who have reached acceptance may revert to a former stage in times of stress. Four periods of extreme stress for the family of a hearing impaired child have been postulated by Moores (1973, cited in Moores, 1982). These are, (a) the process of identification of a hearing loss, (b) school entrance, (c) entering adolescence, and (d) entering adulthood.

Luterman (1979, 1984, & 1987) has written extensively in the area of counseling parents of hearing impaired children. Through working with parents he has identified behaviors and events relating to the family experience with a hearing impaired child which are common to many of those parents.

He cites such examples as, (a) at the initial meeting with professionals, parents often forget what has been said but retain "the feeling of the relationship", (b) parents think they have to operate at a maximum level of involvement and efficiency so that their child's limited potential will be developed and (c) denial of any hearing impairment occurs for parents, relatives and in professionals, "mainly the family pediatrician" (Luterman,1984, p.151).

While programs such as Luterman's have acknowledged the need for support and counseling for many hearing parents of a hearing impaired child, there is little evidence that the experiences of the parents are being recognized. It would appear that such programs exist to help parents cope not only with the deafness of their child but with the difficulties of dealing with professionals in finding and deciding the best ways to help their children.

Professional advice on the management of hearing impaired children should be tempered with sensitivity. Moores (1982) has criticized the power exerted by many professionals. He sees little chance for improvement until the "insensitivity of hearing professionals is reduced and the paternalistic (and maternalistic) attitudes of such people, with their assumptions of superiority are obliterated" (p.178). The imparting of information to parents by professionals is often seen by the parents as condescending. The imposition of the professional's personal philosophy or particular discipline does little to help a family seeking to understand their overall situation and how to best support their child. This point is emphasised by Mendelsohn when she says, "Parents need honest, clear, direct statements from professionals who are at the same time ready to explore questions and be sensitive to the parents' feelings" (1981, p.42). Parents are important and we need to learn to listen to them (Murphy, 1979). If there is going to be a change in the parent-professional relationship regarding decisions which have to be made for the medical management, education and social development of the hearing impaired child it will have to occur at the professional training level (Luterman, 1984).

Gallagher, Cross and Beckman (1983) found that stress in the family with a handicapped child often appeared to increase with the age of the child. Other general factors affecting stress in those families were low family income, divorce and separation. The father plays a limited role in these families either because of his role as the breadwinner or because of the parents inability to communicate with each other. Children of separated or divorced parents are more likely to live with their mother and see less of their father. Excessive stress may interfere with a parent's ability to provide adequate experiences for a young handicapped child and to take full advantage of early intervention programming (Kysela, McDonald, Reddon, & Gobeil-Dwyer, 1989).

Early Diagnosis

Early diagnosis has been identified as an important factor in the future development of hearing impaired children and their families (Gregory, 1976; Mendelsohn, 1981). What happens before and after diagnosis is different for every family and for each family member, yet there are commonalities to be found in the experiences of parents which could assist in the early identification and amelioration of the negative effects of hearing impairment.

The natural science method, that is, hypothesis testing based on observed or related data, has also been used to investigate the experiences of parents during the first years with their hearing impaired children (Connard & Kantor, 1988; Shah, Chandler & Dale, 1978). Surveys and questionaires have served to alert the medical and educational community to the problems surrounding the diagnostic process. Examples of these problems pervade the literature. For instance, Shah, Chandler and Dale (1978) found that families were affected by the inability of referring physicians to accept the parents' opinions, failure to do simple screening tests and physician's reluctance to arrange further referrals to specialists in the field of hearing impairment, such as audiologists and otolaryngologists. Detection of a hearing loss depended on the astuteness and insistence of parents and on the alertness of physicians to the possibility of such a problem. The diagnosis of hearing impairment in young children is often confused (Moores, 1982). Studies have pleaded for early detection of hearing loss and stress the importance of educating physicians in the area of hearing impairment (Luterman, 1984; Moores, 1972).

Early Intervention

In an attempt to counteract problems experienced by special needs children and their famililies there has been a proliferation of early intervention programs over the past two decades, the rationale for which comes from theories, empirical research, expert opinion, and societal values (Peterson, 1987). Early intervention programs may provide for the development of better communication skills. They may allow for social contact with other children, both hearing and hearing impaired, and for the provision or extension of special services (such as speech therapy, auditory training, sign language lessons, and parent counseling) for hearing impaired children and their parents (Freeman, Carbin & Boese, 1981).

The traditional family with a working father and mother as the homemaker is fading and intervention programs need to recognize this by orienting services towards the whole family (Somers, 1987).

Boothroyd (1982) has listed some of the possible problems which can arise secondary to hearing impairment in young children. The sensory deprivation of hearing impairment can become a problem of (a) perception, (b) speech, (c) communication, (d) cognition, (e) emotion, (f) education, (g) intellect, and (h) vocation. All these possible problems may be compounded by parental and societal factors already identified in other studies. These include separation or divorce of the parents, the socioeconomic status of the family and the ability of family members to cope with stress. Because of this Boothroyd (1982) has advocated early and continued intervention in order to arrest "The chain of events" and allow these children to "become independent and contributing members of society" (p.5).

Summary

When looking at the literature on hearing impairment it is apparent that families have often been treated in a very general manner, and seen as a static and definable unit. Yet families are composed of individual members with individual histories, each in a constant state of change and contributing to the family in differing ways. Many studies have referred only to "parents" (Atkins, 1987; Barsch, 1968; Luterman, 1979).

Fathers have seldom been given much direct attention in the literature. Books and articles (Bricker, 1986; Featherstone, 1980; Mori, 1983; Murphy, 1979) have given fathers special reference for only a few sentences or paragraphs. In contrast, mothers have often been the topic or the source of information for an entire study (Morgan, 1987), or a whole book (Gregory, 1976).

In order to support the families of hearing impaired children their is a proven need to seek more knowledge of family dynamics and the individuals who comprise each family. Since there are numerous studies of hearing impaired children and some which are specific to mothers, listening to the experiences of fathers of hearing impaired children should add to our knowledge of such families. Information gained should be of value to both families of hearing impaired children and to professionals working with them.

CHAPTER III

METHODOLOGY

As this study uses a human science method rather than the more traditional natural science method, it is appropriate here to discuss briefly the two methods. A simple way to describe the different approach of the two methods is to equate them to questions. Natural science seeks to explain "Why?", whereas human science attempts to answer the question "How?". Natural science seeks for a causal explanation. Human science seeks understanding of the phenomenon being studied. Understanding of the human science method leads to greater understanding of the phenomenon being studied.

Natural Science

Natural science is based on the search for cause and effect. It is referred to as quantitative research. In order to preserve what the natural scientist sees as objectivity, strict guidelines are followed. The three most crucial assumptions which the natural scientist makes are: (a) that the phenomenon be observable, (b) that it be measurable, and (c) that more than one observer must agree on its existence and characteristics (Valle & King, 1978). Valle & King further point out that if the phenomenon must be observable then psychology becomes a study of behavior rather than a study of the mind. It is answering the question "Why", implying the search for a cause and an effect. In order to do this natural scientists attempt to control variables and report their findings in numbers. They quantify the behaviors they observe.

Human Science

Human science complements this approach by allowing us to deal with questions which relate to the human experience. It is referred to as qualitative research. Phenomenology is one form of human science which looks at the "inner perspective of the person" (Polkinghorne, 1981), focussing on conscious experience and drawing from this common structures or essences. Phenomenology is not an isolated method but rather a number of different approaches to looking at the world as it is lived. Van Manen (1984) sees phenomenological research as a dynamic interplay among the following activities:

1. Investigating a phenomenon "which seriously interests us and commits us to the world".

2. Looking at an experience "as we live it rather than as we conceptualize it". This means that we look at the phenomenon with those who have direct experience of it.

3. "Reflecting on the essential themes which characterize the phenomenon." We learn through careful analysis of the lived experience.

4. "Describing the phenomenon through the art of writing and rewriting". (Van Manen, 1984, pp.2-3)

Qualitative research, especially phenomenological research, requires of the researcher a sensitive art of relationship. This is necessary in order to encourage the coresearchers to disclose their experiences and for the writer to understand empathetically that experience. The presence of caring and respect must be understood by all the coresearchers (Dr. F. N. Walker, 1992).

Husserl was concerned with everyday experiences of the world as they are expressed in our everyday language (Valle & King, 1978). Studying these experiences as expressed by the co-researchers, identifying common forms and describing the phenomenon, is a way of drawing meaning from the experiences and of gaining understanding.

Human science interviewers may follow, either explicitly or implicitly (Becker, 1986), the guidelines outlined by Giorgi, (1975, as cited in Becker, 1986). These are:

1. Fidelity to the phenomenon as it is lived.
2. Primacy of the life world.
3. Descriptive approach.

4. The subject's view of the situation.
5. A structural approach to an interactional context.
6. Biographical emphases.
7. Engaged researchers.
8. Search for meaning. (pp.99-102)

They are all relevant and applicable to the phenomenon being researched, the experiences of fathers of hearing impaired children, and to my role as the researcher. They form a framework for this study.

Method

Research Question

The operational definitions used in natural scientific research are formally structured in order to record the observable facts being studied. These are not appropriate for a qualitative study. In phenomenological research the phenomenon is illuminated by accounts from people who have experienced it (Colaizzi, 1978).

The overall question addressed by this research is: "What is it like to be the father of a hearing impaired child?" A secondary question is, "How are the experiences of the father similar to, or different from, those of the mother?"

The Participants

Phenomenological research uses as many people as are necessary to illuminate the phenomenon. Subjects need to have "salient experiences of the phenomenon in their everyday worlds" (Becker, 1986, p. 105), and be able to develop "some illuminating relation to the phenomenon under study" (Wertz, 1984, p. 36). Coresearchers must be willing to talk about their experiences allowing insight into their life-worlds. With these criteria and the question to be addressed in mind, my co-researchers were the fathers and the mothers of hearing impaired children. My reason for including mothers as coresearchers allowed me to attempt "to discern the phenomenon in contrast to its absence" (Wertz, 1984, p. 36).

Five couples who have hearing impaired children acted as co-researchers. The children vary in age but are all now in Upper Elementary or Junior High School. Each child has a congenital, profound hearing loss and all the parents have normal hearing. They live in two different cities in a Canadian province. All freely expressed their willingness to meet with me and to talk about their experiences with their hearing impaired children. Since the descriptions of their experiences provide the data for this study, they are referred to as coresearchers (Freire, 1970, as cited in Colaizzi, 1978). Their names and family structures and locations have been altered in order to preserve anonymity.

Procedure

Data was collected by audio-taped interview. Having identified and contacted the coresearchers, arrangements were made to meet with them at places where they felt comfortable and relaxed. The coresearchers all chose the time and place for the interview and with one exception all the interviews took place in the family home.

Prior to the interview, coresearchers were asked to complete a Demographic Data Sheet (Appendix A) and to sign a Consent Form (Appendix B). They were also provided with an Information Sheet (Appendix C) identifying the researcher (though she was already familiar to them) and outlining the purpose of the study and the way in which it was to be conducted. The reason for this was two-fold. Firstly, the coresearchers became aware of why and how their information was to be used and secondly, it allowed me to bracket my experience.

Bracketing is an important aspect of the study. Past experience with the phenomena to be studied, as already outlined in the introduction, was intended to make the co-researchers feel comfortable with me as well as to focus the way in which the data was later interpreted. "Common experience, trust, and a commitment to giving as well as taking, support an impulse toward fuller exposure" (Featherstone, 1980, p. 247). Presuppositions which I brought to this study can be identified in the Bracketing section, later in this chapter.

Generating the Data

Dialogal interviews took place between myself and the parents using the method of imaginative listening (Colaizzi, 1978).

Each father and mother talked with me separately for about one hour each, and then the couple together talked with me for a further half hour. These interviews were recorded on audio tape. The coresearchers were free to relate their experiences in their own way and to provide the amount of detail with which they felt comfortable. It was not the intention to pose any direct questions though this did occur, especially when I became intensely interested in the related experience. This occured when specific events mirrored events in the life of the researcher.

I attempted to be present as a "listener" rather than as a "researcher". By giving attention to each coresearcher's nuances of speech and gestures I was able to be present to my coresearchers in the way descibed by Colaizzi (1978) when he counsels the researcher to listen "...with more than just his ears; he must listen with the totality of his being and with the entirety of his personality" (p. 64).

As anticipated before the interviews all the parents spoke freely with me. If any direction or prompting was necessary I posed an open-ended question in order to focus the material. For example, "Tell me about your early experiences with your child", "How has having a hearing impaired child affected you or your family?" or "What was the nature of your interaction with...?"

The interviews varied in the amount of direction or prompting that was required. No reticence or feelings of witholding were noted but at times coresearchers needed a specific question upon which to focus. They appeared to feel that their "ramblings" would not be of interest to me and that they should address some specific topic. The asking of open-ended questions such as, "Tell me about your experiences with the medical community", allowed descriptions to flow. As I listened and sometimes added an anecdote from a similar experience, relaxation began to take place and the researcher was able to revert to a listening role, allowing the coresearcher to relate whatever experiences came to mind.

Following the interviews the coresearchers were asked to write down any further thoughts that may have occurred to them in the following two weeks and to send their notes to me. Unfortunately none of the fathers or the mothers supplied any supplementary data at this stage. One can only speculate on the reason for this - maybe they had already said all that they could remember or wanted to say or, more likely, the constraints of a busy lifestyle precluded the giving of further time to the project.

The audio-taped interviews were transcribed and a copy was sent to each coresearcher with a written request for their reaction to the raw data. If they felt that their experiences had not been clearly or correctly represented they were encouraged to provide clarification. Further, if they felt that an important aspect of their experience had been omitted, they were encouraged to tell me. Envelopes and postage were provided.

Two of the coresearchers responded but with no additional comments and expressed satisfaction with their transcripts. One coresearcher expressed a desire to provide additional material. He was encouraged to do so in written note form but I received nothing. At this stage of the research there were still five families involved. The remaining two families made no response following the receipt of their transcripts. Distance was an inhibiting factor in collecting any further data.

Data Analysis

After transcription of recorded interviews the procedural steps for the analysis of written protocols as outlined by Colaizzi (1978) were followed. These steps can be paraphrased as:

(1) Read the transcripts of the interviews, conventionally termed protocols, in order to make sense, to acquire a feeling for them.

(2) Return to each protocol, extracting sentences or phrases that directly pertain to the phenomenon being investigated. This process is known as extracting significant statements.

(3) Attempt to find a meaning for each significant statement, a process known as formulating meanings. In this process the researcher uses creative insight to find hidden meaning in the words of the coresearchers.

(4) Follow step (3) for each protocol and organize all the formulated meanings into clusters of themes.

- (a) Refer the clusters of themes back to the original protocol.
- (b) Any discrepancies among and/or between clusters may be noted.

(5) These results are all integrated in an exhaustive description of the investigated topic.

(6) Return to the coresearchers with these results and ask for clarification or omissions.

An initial reading enabled the development of a "feeling" for the content of the interviews and the experiences of the coresearchers. The initial reading was followed by several more readings over a period of about three months.

Analysis took place through a hierarchical procedure where the data from each coresearcher was first reduced to simple paraphrases, sentence by sentence, and then identified themes were clustered. (Osborne, 1990). Further reading and interpretation allowed for the revalation of higher order themes within each person's experience. This initial cluster analysis was followed by an across person's cluster analysis of shared themes. Comparison of higher order themes from each coresearcher permitted the identification of shared structures or essences. It is important to remember that I was looking for "structures to present themselves rather than looking for a structure based upon a preconceived theory" (Osborne, 1990).

The identified themes were presented to each coresearcher for additional comments or clarification. No additional data was gathered at this time. A typical response from a co-researcher was, "This is fine".

The final, shared, thematic structures are shown in a tabulated form in Chapter 4. The table is followed by a written synthesis in Chapter 5.

Bracketing

For Wertz (1984, p.42), it is most important that phenomenological research begin "with a bracketing or suspending of preconceptions and a fresh immersement in the lived reality to which the description refers". Following the foundations laid down by Husserl, bracketing allows for the awareness of any preconceptions so that researchers "do not impose them on their research participants" (Becker, 1986). "Objectivity...requires me to recognize and affirm both my experience and the experience of others...experience is there, for all of us, and it cannot be objectively eliminated" (Colaizzi, 1978, p.52).

My personal experience gave me an insight into the phenomenon being researched from the perspective of being a mother of a hearing impaired son and a teacher of the hearing impaired. I have also been a teacher of children with normal hearing and have two other children with normal hearing.

In doing this research I have sought, through reflection, to illuminate the truth about the experience of the coresearchers. In so doing I have been able to come closer to the truth of my own experience. This research has provided me with another lived experience. "Since the lived is always greater than the known" (Wertz, 1984) I have surpassed the former limits of my knowledge.

The presuppositions which I bring to this study are as follows:

- My personal experience gives me insight into the phenomenon being researched.
- As a parent of a hearing impaired child I feel able to talk with other parents about their experience on an equal level, removing the role of "interviewer" and expanding the data collection process to be a sharing of experiences. In this way we are all co-researchers exploring a common experience.
- A hearing impaired child places great stress on the family.
- There is a lack of understanding by educational and medical personnel of the needs of hearing parents of hearing impaired children. This is in part because of our ignorance of the effect of hearing impairment on all aspects of a child's development.
- The need for a sound knowledge of language form, content, and usage is essential for the cognitive development and academic achievement of hearing impaired children.
- The method of communication, sign or oral, is profoundly important to the future social and psychological needs of the hearing impaired child.

- I do not advocate any particular methodology or adhere to a specific ideology. Needs vary between families and among children. The best way to help and support the hearing impaired child is to be alert to these differences.
- I am not deaf. I cannot say what is best for my son. I can only give him as strong an educational background as possible and hope that this gives him the broadest base possible from which to make his own choices. I can support him but I cannot make his choices for him.
- We all have choice available to us but those choices are not necessarily easy to make, especially if our knowledge is limited. In the past I have found it easier to be an "ostrich" with my head hidden in the sand. My past experience has empowered me and I now feel able to look at consequences and make choices.
- Family, and all the pleasures and encumberences which it brings to this life, is very important to me. My family is an integral part of who I am. I have achieved personal growth from being involved in all the stresses and strains which my family has weathered over the past twenty five years, not forgetting all the good times too.

Being both a parent and a professional working with the hearing impaired and their families means that I have "sat on both sides of the table" and have felt both secure and uncomfortable at different times in different "seats". Part of my motivation to do this research project is that I would like to see the "table" removed in order for professionals and parents to work together in the best interests of hearing impaired children and their families.

CHAPTER IV

RESULTS OF THE STUDY

Themes

Analysis of the data through reading and interpretation of each person's related experience, as described in Chapter III, revealed a number of higher order themes. The word "theme" is used to describe what Polkinghorne (1981) calls "structural descriptions". "Theme" is a word which is more easily understood by a reader who is not familiar with phenomenological terminology.

Significant statements which were paraphrased from the initial transcripts of the interviews with the coresearchers have not been included in their entirety in this study. There are several reasons for this. Firstly, the statements are lengthy and would add unnecessary bulk to this document. Secondly, the inclusion of all the statements extracted would preclude the maintenance of anomymity assured by the writer to the coresearchers. Thirdly, the statements themselves constitute a part of the process, the search for hidden meanings in the words of the coresearchers. They are not the final result of the study. However, certain significant statements have been chosen to illustrate each theme and those are included in this chapter.

Clusters of themes, or higher order themes, relate to step (4) of the six steps for data analysis as proposed by Colaizzi (1978), and paraphrased in Chapter III of this study. These higher order themes form the sub-headings for the descriptive analysis of each coresearcher's experience. Colaizzi's step (5), an exhaustive description of the investigated topic follows the individual experiences.

Data Analysis

The data have been analysed in the following manner. After several readings over a period of months the transcribed interview of each coresearcher was reduced to a series of significant statements. At this stage of the analysis it became evident that the amount of material far outweighed the intended size of the project. Therefore it was decided to use only the significant statements extracted from the interviews with the three fathers who were interviewed first. However, since the interviews were conducted with five fathers and five mothers and all that material was read and re-read several times before significant statements were extracted, it is pertinent to note that all the material collected must have made some contribution to the final analysis.

Hierarchical analysis of the statements of the first three fathers revealed higher order themes which were shared among all the coresearchers. Table 1 presents the total analysis in the form of a flow chart.

A within persons analysis for each coresearcher is presented as follows: Significant statements from the transcribed interview are first paraphrased, following which first order themes are identified. For example, for Bart, these are presented as Table 2. Table 3 groups similar themes together in thematic clusters and gives a generalized description of each clustered theme. Bart's experience is then summarized in written form. The same procedure was followed for each father.

A between persons analysis takes the clustered themes from the three fathers and presents them as accumulated themes with a definition of each theme (Table 8). Finally, a further reduction of these themes reveals commonalities between the higher order themes which are then presented as second order themes (Table 9).

The tabular, thematic description of the experience of each coresearcher is preceded by a written biographical description and followed by a written synthesis of the tabulated material.

Table 1

Flow Chart: Analysis of Data

	Within Persons Analysis		Between Persons Analysis	
Co-Researcher	1st Order Themes	Clustered Themes	Accumulated Themes	2nd Order Themes
Bart	Table 2	Table 3	Table 8	Table 9
Eric	Table 4	Table 5		
Joe	Table 6	Table 7		

Individual Experiences of Co-Researchers

BART

Introductory Notes

Bart is the father of Sarah, a young girl with a profound, bilateral, sensorineural hearing loss. Both Bart and his wife have normal hearing.

When Sarah was born the family were living in an Albertan community different from the city where they now live. The move was made in order to facilitate speech, audiological and educational services for Sarah. The instigation to move came from Bart's wife. He had his own business in a town where he felt settled and where he was fully involved in community affairs. They had a new house and he "...figured, this is it. This is a pretty good life and we can handle it." Despite the fact that he saw the daily drive (to access service for Sarah) as becoming "pretty tough" on his wife, and the inability of local authorities to provide service, Bart was still reluctant to move. Given an ultimatum by his wife, "If I wasn't going to move, she was", it took another year before he "finally gave in". In hindsight he now thinks he should have agreed to move earlier.

The relocation has had a profound affect on Bart. The forced move came at a time when the housing market was depressed so the family made a loss on the sale of their new house. The addition of Sarah to the family, combined with the cost of moving, the change in jobs and the loss of income "was really a change" in his life. Bart no longer has his own company. "I'm not the master of my own fate any more." He sees his life now as a "...total change. I've become the sort that I just come home, quiet guy." He is not involved in community affairs as he once was and speaks with nostalgia of past associations. "I knew a lot of people in the town, very involved in the community...my business was doing well, I had a very good reputation." Nowadays he stays home most of the time, "I don't go out, I'm not involved in nothing" , and attributes his changed condition to his daughter's needs. "...it's been such a big deal with her (Sarah) and the whole thing of coming here and all the changes...I just lost my community drive, I don't do a thing. I miss it now. I miss what I had now."

However, he is not in a hurry to re-involve himself in community affairs. He expressed feelings of guilt about taking time away from the home. "When are you going to do it? Maybe you should be doing something with the kid. You don't want to maybe go and get too involved in something and sort of leave her out...I don't want to sit back when I'm fifty or sixty and say, jeez, I missed some time."

Playing with Sarah did not come naturally to him, "I'm not one of those guys that's out there on his hands and knees playing with his kid like some guys do", but as she grows older and communicates more with him, he finds that he is "enjoying her a lot more". He exhibits fatherly pride in her achievements. When she said she wanted to work with him when she is grown-up he saw that as "the writing on the wall" and plans to establish a business where they can work together.

He views himself as the provider for his family and has left his wife to do most of the day-to-day work with Sarah. Recently she has returned to school and he has taken on more responsibilities with regard to driving Sarah but still leaves the reading, background research and most of the extra teaching duties to her. "I'm not much for reading but (my wife) reads them...and then she tells me". He recognizes the extra work that has to be done to help Sarah develop language and worries about her future. "If you think you're going to...that this kid will just...all that you have to do...if you just get it in the right environment that it'll take off...then you're doomed to fail...I still worry about next year...it never ends staying on top of things."

Our interview began slowly but once started Bart spoke openly and eloquently of his feelings when Sarah was small and of what he sees as the "struggle" of parenting Sarah. Bart is a very direct man, crediting his business success to his ability to be "specific" and not "pussy-foot around". Despite the fact that he sees himself now as a quiet guy he found searching for a diagnosis for Sarah required the necessity of "..putting your foot down and shouting and hollering and its easy for me because I'm big enough." he also found it an "emotional thing".

When asked for advice for other fathers of hearing impaired children Bart replied flippantly, "Do whatever their wives want. It makes it pretty easy." In a more serious vein he emphasised the need to be open minded, and the need to "deal with it" (the hearing impairment). He said, "It's tough! But once you kind of decide that you want to do something and you want to do what's best for the kid, and be willing to make the sacrifices, then you become willing to do it. The more willing you become, the easier it gets".

Significant Statements from Bart's transcribed interview are organized into thematic abstractions in the following two tables. (Table 2 & Table 3).

Table 2

Thematic Abstractions of Bart's Experience

Excerpts from Transcribed Interview	Two Levels of Abstraction 1. Paraphrases	2. Themes
B1: Just like sort of funny how you could vacuum and never wake her up and you know, you could do all sorts of things and it wouldn't distract her. So that, you know, starts your mind working a little bit, wondering.	He becomes concerned because child does not appear to be responding as a normal child. Concern is mostly kept to himself at this stage.	Apprehension
B2: So from about six months to twelve months we kind of go to the health Unit and they'd say, no she's fine. But they have a very limited intelligence at the Health Unit and they're good for fluoride and immunization shots. But...you can quote me on that...but...and then once she got to be a year old, then it was really, we were getting pretty worried about her and started pursuing it and finally we got our doctor to finally agree to have her tested.	Parents share concern but are unable to convince medical personnel that there is something different about their child. Numerous visits to both the health unit and the doctor are not supportive.	Frustration with medical personnel
B3: Persistence...at first the doctor wouldn't believe it because the kid was so bright. He'd be playing with her and never suspect she had a problem.	Even though the parents are expressing concern the doctor fails to react. Anxiety is heightened as the parents are forced to continue seeking for an answer.	Frustration with medical personnel
B4: All of a sudden you have the concern, the fear, and then you have your fears confirmed. It wasn't too great. You keep hoping there's nothing wrong and then you find out, and then the process begins of tryng to find out what it is.	Continued searching heightens the sense of fear and anxiety. When the diagnosis is made there are still many unanswered questions	Fears are confirmed

B5: Involved with the medical community..that to me...somewhat of a sore. I respected the man as a doctor... I used to run an ambulance...I had a lot of respect for his abilities...yet he really drug his but on getting Sarah in there.	Frustration is increased when the doctor whom he had previously respected also failed to listen to the parent's concerns.	Frustration with pace of medical procedures
B6: We really had to ride him. it seemed like every step of the way you were fighting somebody to get something done.	Instead of receiving service from the medical community the parents are forced to continue asking for help.	Frustration with pace of medical procedures
B7: It was just a hassle all the time...put your foot down and shouting and hollering...its easy for me because I'm big enough. Its really tense trying to get things done.	He expresses how he managed to get people to listen to him and wonders how others are able to cope.	Conflict with medical personnel
B8: The whole ordeal of going through that children's hospital in a big city and all the testing there, that's an emotional thing. Boy thats tough...you sort of get the impression that this is a worst case scenario.	He remembers the anxiety of taking the child for in-depth testing with various medical personnel. The numerous tests add to his feeling of fear.	Fear of the diagnostic process
B9: I think the one thing that saves the place is they have a bunch of ladies in there that volunteer...they just get you a cup of coffee and they help you out and look after the kid while you're talking to the doctor...and they help put you at ease right away. You drive for three or four hours to get there and its pretty cold and you're afraid of what they're going to do and whats involved.	Feels reassured and comforted by non-medical staff. Simple caring, coffee and child care, helps to ease the tension.	Appreciation of hospital volunteers
B10: I think you're more afraid of what they're going to tell you because you keep hoping.	Experiences feeling of tension an apprehension while waiting for the tests.	Fear of the diagnosis

B11: I have a real tough time with it. Deaf. You know having this deaf kid.	Expresses deep emotional feeling.	Trauma of the diagnosis of deafness
B12: All you think about is all the deaf people you knew...and you go, Oh God, I don't want to live like that.	Relates present situation to what he sees as a negative experience.	Fear of deafness
B13: The unknown. Everyone's afraid of the unknown.	Justifies feeling of insecurity.	Fear of deafness
B14: ...feel intimidated...you've got all these different names you're going to see. Not one of these people have you ever met. Who are they? Are they good? Are they clerks? Are they residents? Are they real doctors?...and I think I want some guy who's 55 and knows everything.	Feels insecure waiting to see several medical personnel of whom he has no knowledge. Adds to the anxiety being felt for the child.	Fear of the "system" (medical bureaucracy)
B15: They all go through their (observations)...and there's a kind of talk back and forth...you're so overcome by the whole thing, whether you ask any questions that you want to ask at that time - I doubt it.	Feels powerless and unable to react in the situation.	Disempowerment
B16: I was dumbfounded...its sort of assumed that you already know all this... deafness...all this technical jargon's been laid on you...and they ask if you understood...like anyone else you lie and say yes because you didn't want to talk about it anymore anyway.	Experiences feeling of inferiority because of lack of specialized knowledge. Unable to formulate questions to advance knowledge at that time.	Intimidated by the "system". Disempowerment
B17: The first day you've put your fingers through the wall. You've cried, you've done everything in one day. You need time to unwind and collect your thoughts.	Feels emotionally drained and exhausted by the experience.	Trauma of the diagnostic process
B18: We had the brain stem test done. It confirms everything, it dashes all your hopes.	Aware that now has to cope with the situation.	Despair

B19: It was pretty traumatic to see that little girl sitting there and wearing all this hardware.	Expresses emotion when child first wears hearing aids.	Fear of the "system" (diagnostic process)
B20: Wear the FM transmitter, I never really did. I was somewhat intimidated by wearing that thing. (Wife) did some. I never could get into it, I never could.	Unable to fully accept child's deafness. Not able to wear "equipment" in public places.	Fear fo medical technology
B21: Sixty miles one way to school every day...Every Friday to the big city. (wife) drove 90% of the time.	Recognizes the time and effort made by his wife.	Father's Recognition of Mother's role.
B22: We didn't do it for ever. It was just too much...in that first while we did everything.	Family is stressed trying to provide service for their child.	Stressed by caring for deafness
B23: Pretty well set...pretty selfish. I have to look at it somewhat selfishly...my business was doing well, I had a good reputation, I never had to look for contracts. I was on the fire department. I was president of the Credit Union...put a lot of effort into that...I knew a lot of people in town...very involved in the community...we had our new house and we figured this is it. This is a pretty good life and we can handle it.	Aware of the resentment he felt when having to face the possibility of moving to a larger centre in order to access medical and educational services for his child. Child's needs impinged on his position in the community.	Changes in Lifestyle - disruption, re-adjustment
B24: She (wife) said if I wasn't going to move she was...so I had to finally. It took another year but I finally gave in.	Experiences pressure from wife and expresses his unwillingness to move.	Marital conflict/ lifestyle changes
B25: Total change. Its been a roll reversal. I've become the sort that I just come home...quiet guy. I don't do anything anymore. I don't go out. I'm not involved in nothing.	Having to leave the community where he felt secure and established has altered his attitude and personality.	Extrovert to home-body Social withdrawal

B26: Its been such a big deal with her and the whole thing of coming here and all the changes. I just lost all my community drive....I miss it now...I miss what I had now.	Looks back with nostalgia on past lifestyle. Recognizes to enormous effort it has taken to make the move.	Lifestyle change Social withdrawal
B27: You don't want to go and get involved in something and sort of leave her out and miss...I don't want to sit back when I'm 60 and say, "I missed some time", so I don't know if I'll ever do anything at all until she is older.	Expresses need to be involved in his child's development. Resigned to having to make personal sacrifices.	Feeling of resignation
B28: Lately its been good because now she's older. I'm enjoying her a lot more now she's older. We go and do something and work on something and she gets the tools out now. Not only is she a little more fun to fool around with but she's also helpful.	Experiences pleasure in being able to relate to his child. Proud of her developing abilities.	Positive interaction with child
B29: Five, six years ago..how am I ever going to do anything with this kid because I can't talk to her.	Reveals feelings of rejection because of his inability to communicate with his child. Frustrated by the situation.	Communic-ation/ frustration
B30: I said, "What do you want to be when you grow up?" "I want to work with you." And I thought, the writings on the wall, so you know before she's done school I'll have some business she can work at.	Gaining confidence as child develops more language and ability to communicate with Father. Prepared to alter lifestyle again in order to support child.	Taking respons-ibility for child's future
B31: She's going to struggle all her life until whenever. She's going to have problems, she's going to struggle.	Recognizes that there will be continuing problems to be overcome.	Pessimistic scenario for child
B32: She's going to struggle socially because I don't want her...the last thing I want her to be, and I think thats the one thing that bothers me the most is the deaf community. I have no desire to see her there at all.	Afraid of involvement with the deaf community while recognizing that his daughter may feel more comfortable with deaf peers.	Fear of stigma of deafness and deaf community

B33: They're such a tight knit group that they just...anybody who is hearing is caste out. I don't want to be cast out. I want to be part of her life until I'm dead.	Unable at this stage to envision where his child will fit into the community when she is older. Feels protective and possessive at this time.	Fear of exclusiveness of deaf community
B34: Once I decided to move - (my wife) had already decided - I've gotten over the fact that I had to move. Once I did it its done. Its really been great for (child). She's come a long way and if we'd stayed she'd be in the deaf community. I'm convinced. So there's no regrets. No remorse at all.	Remembers past resentment but expresses present content with the decisions that were made. Feels that the move has allowed his child to remain a part of his community (hearing).	Post decision satisfaction
B35: This is the first year its been a little more me because (my wife) has gone back to school. But up to now...I give her a lot of credit, she's handled 90% of the stuff with teachers. I like to know whats going on but (my wife has) done the greatest percentage of the work. I think between what she's done and the schooling here, she's where she's at...If she wouldn't have put in that effort she wouldn't be where she is now.	Has been forced into increased involvement with child's education because of his wife's personal commitments. Recognises her past work.	Father's Recognition of Mother's role as primary parent
B36: Trying to decide which school, that was hell. I don't think you ever wonder what to do next.	Experiences insecurity and frustration when faced with a change in schools. Recognizes that this will happen again.	Fear, anxiety about educational decision
B37: We bought a lot of books - I'm not much for reading books but (my wife) reads them and then she tells me...she hangs it on the fridge, what they're working on.	Recognizes the extra effort which his wife has had to make. Relies on her to read and precis information for him.	Father's Recognition of Wife's Role feelings of inadequacy or avoidance
B38: I had to learn to be pretty open-minded. You have to look at a lot of things.	Aware of the need to investigate and accommodate options.	Changes in Lifestyle accommodations

B39: You've got to deal with it and want to deal with it and want to learn about how to deal with it. Once you kind of decide that you want to do something and you want whats best for the kid, and be willing to make the sacrifices, then you become willing to do it. The more willing you become, the easier it gets.	Recognizes the complexity of his situation and advocates personal involvement.	Changes in Lifestyle. Sees it as a struggle of will
B40: I still worry about next year. Its never ending staying on top of things.	Worries about the future.	Anxiety about future "the burden"
B41: You have to get informed and then you have to make a decision. You gotta take the time...you gotta go and look at it all...be as informed as you can because you're the one that's going to have to make the decisions.	Recognizes the work and personal commitment needed to bring up his child.	Awareness of importance of information for decision making

Table 3

Higher Order Thematic Description of Bart's Experience

Thematic Clusters	Generalized Descriptions
FEARS:	
1. Fear of the Unknown (Excerpts from Table 2: 1, 13)	Attempts to justify feelings of apprehension and insecurity and a fear of his child's deafness by relating to others "Everyone's afraid of the unknown".
2. Stigma of Deafness (12)	Lack of knowledge about deafness and deaf people, or past negative experiences, cause him to see deafness as stigma.
3. "The burden" (40)	Anxiety about the future which he sees as being an ongoing challenge to be dealt with. continually.
4. "The System" (14, 19)	Feelings of intimidation when faced with unknown people and procedures related with diagnosis and management of child's hearing loss.
5. Diagnostic Process (8, 10)	Taking the child through the diagnostic process indicates that there really is something wrong and tension is increased while waiting for a diagnosis.
6. Technology (20)	Wearing the transmitter in public places. adds to the 'difference'.
7. Deaf Community (32, 33)	Recognises that child may feel more comfortable in the future with other deaf people. However, is not yet able to accept this and sees the deaf community as a threat to their future relationship.
8. Educational Decisions (36)	Struggles to make choices about the best educational placement for child, and one with which the family is comfortable. The process is repeated wnenever the child changes schools. Emphasises the child's dependency on parent.

TRAUMA:

1. Diagnosis Confirmed (4, 11)	Fear and anxiety experienced prior to the diagnosis are compounded by ignorance of the condition and the ramefications of the diagnosis.
2. Disempowerment (15, 16)	Feels completely overwhelmed by the medical personnel. Shock of diagnosis and unfamiliar surroundings render parent unable to react in normal way.
3. Diagnostic Process (17)	Series of medical appointments exhaust all systems and he feels need for "time-out" to recharge and try to come to terms with the diagnosis
4. Despair (18)	Irrefutable medical test leaves no room for false diagnosis. Confirmation of fears leaves feelings of despair.
5. Being Parent of Deaf Child (37)	While recognizing his wife's work he displays sense of inadequacy. He has been able to avoid closer involvement by avoiding a task which does not come naturally to him and which he finds difficult. (reading medical & educational texts).
6. Family Stress Caring for Child (22)	Initial attempts to do as much as possible for the child and learn all the new techniques cause an overwhelming stress.

FRUSTRATION:

1. Medical Bureaucracy (2, 5, 6)	Frustration with the doctors because they were not reacting to parental concerns, questions were not being answered and unasked questions were not being explored.
2. Communication (29)	Feels frustated by his inability to communicate with his child. Now begins to realize the need to put extra effort and time into learning how to communicate with child.

CONFLICT:

1. Medical Bureaucracy (3)	Having watched the doctor help others is moved to anger when he feels his own child is not receiving the same attention.

2. The System (7)	Resents having to push for service, explain needs, repeat history. Ongoing explanations and requests make him feel as if everyone is against him rather than there to help.
3. Career vs. Child (23)	Unable to readjust lifestyle to accommodate needs of the child. In retrospect is able to appreciate the selfishness of his previous attitude.
4. Marital (24)	Experiences conflict with his wife as they move at a different rate in their appreciation of the child's needs.
5. Social vs. Recluse (25, 26)	Moving the family causes social withdrawal. From previous extrovert now sees himself as a homebody and speaks with nostalgia and some resentment for the lost lifestyle.
RETROSPECTIVE LEARNING:	
1. Recognition of Volunteer Service (9)	Simple caring of hospital volunteers is remembered with gratitude.
2. Recognition of Mother's Role (21)	Is now able to appreciate that the time and effort expended by his wife has played a big part in his child's development.
3. Acceptance of Lifestyle Changes (27)	Because of his need to be involved with his child is now resigned to changes already made and those which he sees in the future.
4. Possibilities for Interaction with Child (28)	Increasing confidence in his ability to communicate with child helps him look forward to future involvement.
5. Accommodations in Parenting, Career, Lifestyle. (30, 34, 38)	Now able to see ways in which he can prepare child for an independent future. Feels satisfaction at past decisions and present situation. Expresses need for open-mindedness.
6. Pessimistic Scenario Not the Actual (31)	Sees many problems ahead but feels better prepared to handle them. Past experiences are now coloured by gretaer understanding.
7. Accepting Responsibility as Parent of Deaf Child (35)	In discussing his increased involvement with child reveals an awareness of past avoidance of responsibility.

8. The Battle isn't Hopeless (39)	Has had to struggle with his personal needs and the neeeds of his child. Now sees that the two are closer together as he begins to develop a closer relationship with the child.
9. Aware of Importance of Information (41)	Recognizes the time involvement which is needed in order to seek and absorb information necessary for decision making.

Bart's Experience - Written Summary

Bart's experience as Sarah's father can be divided into three different stages. The time before Sarah's deafness was diagnosed, the time around diagnosis and the present post-diagnostic stage.

The pre-diagnostic stage is exemplified by feelings of fear and apprehension. These are emotions to which it is easy for us all to relate and Bart excuses his feelings by relating them to others: ("Everyone's afraid of the unknown".) Feelings of anxiety began as the family first became aware of Sarah's differences. Bart describes doing his own secret tests with Sarah to see if she reacted to sounds. As his concerns increased he kept them to himself and found it hard to discuss them with his wife. Beginning then, and continuing to this day, Bart sees Sarah's deafness as a burden for the family: ("I still worry about the future. Its never ending, staying on top of things".)

Apprehension was not eased by taking his child to the Health Unit and asking for help. Even though this all took place several years ago, Bart still remembers very clearly the reactions of the Health Unit staff. Their lack of concern still angers him and his comments on that time are scathing and tinged with bitterness: ("They have very limited intelligence at the Health Unit and they're good for fluoride and immunization shots...you can quote me on that...".) As concern increased with the child's age he and his wife had to request, and put pressure on, the family doctor to send Sarah for further testing. Bart sees this as something which they had to "pursue" and which took "persistence": "We really had to ride him. It seemed like every step of the way you were fighting somebody to get something done".

When the doctor did take action by referring Sarah to a hospital clinic the fear was not relieved. The doctor's action only served to heighten the level of anxiety. If the doctor was agreeing to further tests then there really must be something wrong. Despite growing suspicion that there was something different about his child he continued to hope that that was not true. However, even that hope served to increase the tension because, "You're more afraid of what they're going to tell you".

The diagnostic process itself increased the anxiety and Bart describes it as "an emotional thing...you sort of get the impression that this is a worst case scenario". He felt intimidated by the proceedures and by the medical personnel who were unknown to him.

When the diagnosis was finally made hopes were dashed and fears confirmed: "It wasn't too great. You keep hoping there's nothing wrong and then you find out, and then the process begins of trying to find out what it was".) Fear and anxiety experienced prior to the diagnosis are compounded by ignorance about deafness and the ramifications which his child's deafness will have for all the family. Bart still expresses deep emotion about Sarah's deafness: ("I have a real tough time with it. Deaf. You know, having this deaf kid".)

Knowing that it was likely that Sarah had a hearing loss did not prepare Bart for the way he felt immediately after he was informed of the diagnosis. He was "dumbfounded" and felt powerless and "overcome by the whole thing". He remembers being unable to formulate all the questions he knew that he should ask: "All this technical jargon's been laid on you...and they ask if you understood...like anyone else you lie and say yes because you didn't want to talk about it anymore anyway".

The diagnostic process was traumatic for Bart. There is an underlying resentment for the medical staff who did not seem to appreciate a parent's needs. They seemed to be more concerned with imparting information about deafness and how to help a child, failing to recognize the parent's inability to reason at that time. Feelings of exhaustion and of being emotionally drained are expressed eloquently by Bart: "The first day you've put your fingers through the wall. You've cried, you've done everything in one day. You need time to unwind and collect your thoughts".

The unfamiliar surroundings, unfamiliar personnel and unfamiliar terminology combined to overwhelm Bart. He felt disempowered and unable to express himself in his usual forthright and direct manner. The irrefutable medical test dashed hopes and left a feeling of despair. The feeling of being overwhelmed persists to this day as the family attempts to do everything which they feel they should for Sarah in order to assist her linguistic, cognitive and social development.

The diagnostic period was a time of conflict. The conflict, started with medical personnel as the parent's tried to convince their doctor that their child had problems: "Persistence...at first the doctor wouldn't believe it because the kid was so bright. He'd be playing with her and never suspect she had a problem" and increased to become conflict with the medical "system". Bart remembers how "tense" it was "trying to get things done." Eventually this conflict spilt over into the life of the family as Bart and his wife expanded differently in their understanding of Sarah's needs. Bart, who had an established a life style which he enjoyed, was reluctant to make accommodations for his child. Today, with hindsight, he admits his inability to see beyond his own needs. He remembers that he was "pretty well set...pretty selfish. I have to look at it somewhat selfishly."

Starting with an inability to make changes in his career and community involvement, problems escalated to become marital conflict as Bart refused to understand his wife's dilemma. She saw that Sarah needed more educational services than their home town was able to provide. Bart recognized this at one level as he was able to go with his wife to different provinces looking for a suitable educational program. However, he was not able to make any committment to moving their family. His wife told him that "if (he) wasn't going to move, she was" and faced with that ultimatum Bart finally "gave in". This was not a fast decision and was a time of stress for the entire family. Bart felt pressured by his wife and child and the whole situation but realized eventually that if his family was to stay together then he would have to move too: "It took another year but I finally gave in").

Because of his need to be more involved with his child he is now more resigned to the changes which his family has had to make. When he says, "I don't want to sit back when I'm sixty and say, 'I missed some time'", he seems to be expressing a commitment to increased involvement in the future.

While not expressing resentment for the changes which Sarah's needs engendered ("...there's no regrets. No remorse at all") Bart speaks with nostalgia as he looks back on his old lifestyle. The trauma is still evident when he says: "Its been such a big deal with her and the whole thing of coming here and all the changes...I miss it now, I miss what I had now."

In the present post-diagnostic period Bart shows accommodation and acceptance. He expresses gratitude for the simple caring of volunteers in the hospital. The people who provided ordinary things such as a cup of coffee or directions to a certain department are remembered as an oasis of normality within the strange and stressful atmosphere of the hospital. He also recognizes the time and effort expended by his wife in teaching their child. He sees his wife's involvement as a major contributing factor to his child's sucessful development: "If she (his wife) wouldn't have put in that effort she (Sarah) wouldn't be where she is now."

Bart sees the changes that the family has made and his personal change in lifestyle as a necessary struggle, but a struggle which has its own rewards: "Once you kind of decide that you want to do something and you want what's best for the kid, and be willing to make the sacrifices, then you become more willing to do it. The more willing you become, the easier it gets." He recognizes that actively working with and for his child is not something which happened easily for him.

That he now feels comfortable with his past decisions is evident as he advocates involvement for other fathers. He tells them to "be as informed as you can because you are the one that's going to have to make the decisions." He counsels them to be "open-minded" and to "look at a lot of things." However, open-mindedness is not so easy to practice as he tries to come to terms with his daughter's possible future involvement in the deaf community: "I think that's the one thing that bothers me most is the deaf community. I have no desire to see her there at all"). He sees them as a "tight-knit group" where "anyone who is hearing is cast out." This frightens him and he sees it as a personal threat: "I want to be part of her life until I'm dead."

Anxiety is still evident when he speaks of the future but it is tinged with acceptance rather than bitterness: "She is going to struggle all her life...". He is moving towards positive involvement in his daughter's life: ("This is the first year that it has been a little more me") and expresses pleasure at the time they spend together, "Lately its good because now she's older". Now he is making positive plans to create "some business she can work at" when she is older, but his underlying feelings for the future are that he "still worry(ies) about next year. Its never ending, staying on top of things".

ERIC

Introductory Notes

Eric is the father of three children the oldest of which is his daughter, Claire. Claire is profoundly deaf in both ears and has been so since birth. She is the only deaf person in her family.

Neither Eric nor his wife had any prior experience or knowledge of deafness. Eric left school illiterate and has only become literate since his marriage to Janice. They were married when Janice was very young and were not prepared in any way for the problems with which they were to be confronted. Eric always saw himself as the provider whose role was to earn money in order to support his family. He still sees this as one of his roles but has widened his perspective and is now involved with his family in various ways, one of which has been greater involvement with Claire's educational program. As Claire has grown and developed so have Eric and his wife.

Eric speaks easily of the illiteracy that helped him appreciate the need for good language skills for his daughter. He knows, first-hand, the consequences of poor language skills and he did not want those for his daughter. At first he was not able to express that empathy and understanding of his daughter's language needs in positive involvement but now a role reversal has taken place. Eric does not have a high level of formal education. He says that he was "..raised with experience, not education." He "...firmly believe(s) that you learn more out of school than you do in school".

He describes his involvement with his daughter as changing from one of supporting his wife in the best way he felt able, earning money (sometimes by working up to three jobs at a time), to the present situation where he works full-time and has also taken over from his wife as the chief advocate of educational services for Claire. In this role he is doing things which he has never done before. Attending meetings with teachers and other educational personnel, being a panel member, lobbying the school board for speech and language services within the school system are ways in which he has increased his involvement and which he credits for his personal and emotional growth.

Both Eric and his wife have spoken to me before about their experiences with Claire. They both welcomed the chance to express their experiences in this study. Underlying everything that Eric talked about in our interview was a cynism about the competency of professionals and a sense of pride in the way in which he and his wife have handled their struggles to obtain medical and educational services for their daughter.

Significant statements from Eric's transcribed interview are organized into thematic abstractions in the following two tables. (Table 4 and Table 5).

Table 4

Thematic Abstractions of Eric's Experience

Excerpts from Transcribed Interview	Two Levels of Abstraction	
	1. Paraphrases	2. Themes
E1: The frustrations began when we found out Claire was deaf....and thats where the frustrations came in, with the red tape and everything else.	Remembers the diagnosis as a time of dealing with a system which he could not control and which did not appear to serve his needs.	Frustration with the "system".
E2: ...You've got to deal with so many professionals that aren't really professionals and what they think they are. They have only got a title...I figure they are professionals because they have that title...I was a little niaive and thinking that the professional knew what he was doing.	Harbours resentment against members of the medical profession because he sees them as the cause of his frustration. Indicates a lack of communication between the professionals and the parents.	Frustration. Expresses bitterness.
E3: ...family doctor...made a prediction that Claire was slow in learning because I had said my experiences were slow in learning. He never diagnosed the child as deaf, he diagnosed the child as a slow learner.	Feels that he shared all his knowledge with the doctor but the doctor did not use his expertise.	Frustration Expresses bitterness & feelings of denegration.
E4: ...where the frustration comes in is that where he didn't have a clue he wouldn't admit it that he didn't have a clue...always have to make some kind of front...some kind of statement..	Sees the first/wrong diagnosis as a statement by the doctor because he really didn't know what was wrong with the child. Does not feel any support from or empathy with the doctor.	Frustration.. Despises doctor for lack of communication..

E5: I argued with him at the time but I really didn't know what to argue with him because I didn't know myself...you have to have the appropriate questions to get the appropriate answer...because you don't know what to ask or how to ask it...because you don't have that, you don't perceive to know what is wrong with your child...you just...there's something wrong.	Feels caught in a Catch-22 situation because of his lack of scientific knowledge. However, also feels strongly that he has something to contribute and that he is not being listened to by the doctor.	Disempowerment.. Feelings of inferiority.
E6: All the red tape you have to go through to get your child tested because they just don't take you at your word.	Thinks that the diagnostic process would have been easier on everyone if someone had listened to the parents.	Frustration with the "system".
E7: I really didn't understand it at that time. (diagnosis).	He is faced with an entirely new situation..	Overwhelmed by lack of medical knowledge.
E8: I had three jobs...I guess I was more or less burying myself in a lot of involvement of what I had to do around myself to...not think about how it was going to be with Claire's future. Not consciously I wasn't doing it..	Upon reflection feels that he was avoiding coping with his child's problems at that time.	Overwhelmed by child's problems..
E9: At the time it was a lot on (my wife). I am very proud of (my wife) and how she dealt with it at her age.	Recognizes and praises his wife's involvement.	Father's Recognition of Mother's Role.
E10: It was weird going into that school. You would hear the bell go and you don't hear anything else. There's no children laughing or talking or anything else. It was so quiet. It just didn't rub me the right way.	Experiences discomfort when around deaf children in a deaf school. Unable to relate to a different situation and feels alienated.	Ignorance of deaf community causes discomfort..

E11: The professionals at (child's present school) were down on the (signing) school. They pumped into us that it was not a good place to go for our child... They didn't have any answers for us. We had to dig something up and we were quite frustrated. We were sure the (other) school wasn't any better.	Aware of tensions between different educational philosophies. Parent's are unable to find what they see as an appropriate program for their child.	Frustration with the educational system..
E12: She (child) never had any contact with hearing kids. She stopped talking and babbling and she was doing more signing, she got closed in. She didn't see the incentive to babble or do any talking because she was hanging around with all the deaf kids.	Resents child's increasing use of sign language which he is unable to comprehend.	Fear of deafness and deaf community.
E13: Our time was running out and we needed to find something. We finally got mad and wrote a letter to the trustees.	Frustrated by the lack of appropriate program for child.	Lack of service leads to parental action..
E14: There was an image that everyone was working together. Everyone was working to a goal...So everybody was excited because we had everything we needed pretty well in this program and Claire could function in this school.	Experiences cooperation and good communication in child's new school..	Feeling of satisfaction at results of work..
E15: And to top it off, there were hearing children there. We were excited about that because we wanted Claire to have hearing children's mannerisms and just to be as normal as could be.	Gains reassurance when child is mixing with hearing children.	Fears stigma of deafness and deaf community.
E16: We had to fight for that...Because they didn't understand what we were trying to achieve.	Unable to communicate their concerns for their child's educational needs.	Fighting the educational system.

E17: You can't argue with these people because they have to answer to so many people because of public funds...They generally make a wrong decision because they don't have factual information coming at them. And I don't feel they make a very good job of researching what they're making decisions on..	Elected officials lack information on which to base their decisions because it is not given to them or they do not listen to available information..	Frustration with elected officials.
E18: I've had a couple of meetings with _____ and tried to tell them, you know, its frustrating, its difficult, its time consuming. Doing my job, going to meetings, it was really frustrating to always have to spell out your life to somebody else or what they're doing to you.	Experiences resistance in meetings with "officials". Is forced to take a strong personal stance and feels diminished having to reveal personal information to strangers.	Feels diminished having to reveal feelings in public in order to gain service for his child.
E19: And you're really not in a position to tell other professionals what they are and what they're not doing.	Expresses feeling of inferiority to professionals.	Overwhelmed by professionals .
E20: (battles?) Because we were breaking new ground is why.	Perceives himself and his wife as pioneers who are leading the way for others.	Fighting for service.
E21: (Wife) doesn't go to anymore meetings...she found it really overwhelming...she was always surrounded by deaf, deaf, deaf...and thats all it was...it was a kind of overpowering thing for quite a while.	(Wife) has had to remove her self from total involvement with the situation.	Overwhelmed by total involvement in child's needs.
E22: I've gone to all the meetings...I have to do something...I can't just let ___(wife) do everything and just provide for the home.	Recognizes that he has not been involved in the past. Now trying to take a more active role with child's needs.	Father's Involvement.. Feeling more secure..
E23: At the beginning you're like a sponge...you're taking everything in...and now I try to size the information and you grow on that.	His knowledge is increasing and he is gaining confidence.	Father's Involvement. Increased knowledge.

E24: A father...was talking about his son who was going through ___ School, and he was talking about children coming out of there and being illiterate and at that time they were not getting a High School Diploma. The professionals would try to tell you these things in a professional way...and that concerned me a lot because I was illiterate myself and I know how important it is to be able to read and write.	Information which has been given to him by professionals is made clear when he hears it from another father. The needs for language development and literacy for his son is very important to him because of his own experience.	Father's Involvement. Is able to relate to child's needs.
E25: I did (have the opportunity to share with other father's) but I wasn't supposed to be there...(wife) was sick...I was put on a panel...four mothers, one daughter and one son. We were talking to new parents and what we thought was important for our children.	The opportunity to share with other parents occurs by accident when his wife is unable to attend.	Father's Involvement occurs by chance.
E26: I broke up...It was the first time I had talked to anybody about my perspective, my views on what I've gone through over the years...when it came to me I was choked up...because it brought back all the frustrations and everything else that I've gone through in years dealing with these professionals.	He had never been asked about his feelings or experiences and when the opportunity occurred he found his emotions hard to control..	Father's Involvement provides chance to examine feelings.
E27: I'll never forget dealing with that one doctor. We came into the office and he says, "What took you so long to get your child in here?".	The doctor is frustrated not to have seen the child earlier. The parents who have battled their way to this appointment find his remarks insensitive to their situation.	Frustration with medical personnel..
E28: You have to be effective and you have to say it right...You can't be mad, you can't be upset. You have to do it right if you want to acheive something.	Feels the onus is on him to be informed and to keep calm.	Realizes how to communicate with professionals

E29: I didn't even expect those emotions to come out.	He is surprised by the emotions he has locked inside him.	Father's Involvement provides opportunity to examine feelings.
E30: You gotta make time to if you want to be involved and get involved...You have to do what you can, when you can...providing the child with experiences no matter what you are doing.	He now sees the importance of spending time finding out about his child and her needs.	Father's Involvement leads to realization of child's needs.
E31: Be involved.	Recognizes that now he is involved with his child it is better for everyone.	Father's Involvement leads to positive assertion of father's role.
E32: You can't depend on educators to educate your child.	He is aware of the extra effort which is needed by the family in order to provide the best learning environment for his child.	Father's Involvement. leads to positive assertion of father's role.

Table 5

Higher Order Thematic Description of Eric's Experience

Thematic Clusters	Generalized Descriptions
FEARS:	
1. Deaf Community (Excerpts from Table 4: 10, 12)	Fear of deaf community caused by ignorance and lack of acceptance that child's needs may be different from those of the other members of the family.
FRUSTRATION:	
1. "The System" (1)	Frustrated by a system of which he was ignorant and which he did not perceive as helping him to understand what he should do to help his child.
2. Bitterness (2, 3)	Expresses bitterness at the way in which medical professionals failed to provide help for his child and failed to look beyond the father's history at the child's symptoms.
3. Communication (4)	Despises the doctor for failing to express his lack of answers or referring to another doctor. Feels doctor treated him as an inferior rather than as a concerned father.
TRAUMA:	
1. Disempowerment (5, 13, 20)	Ignorance of medical terms and educational needs of child hamper communication. Knows that the lack of answers was partly because he did not know the right questions to ask.. Frustration and anger at lack of correct program for child leads to direct appeal to school trustees.
2. Overwhelmed (7, 8, 19, 21)	Initially, ignorance of meaning of the medical diagnosis and inability to help child are overwhelming. He concentrates on supporting the family financially, thus avoiding further involvement or responsibility.

CONFLICT:

1. The "System" (6)	Feels frustrated by the "system" because the family's concerns were not acted upon. Medical personnel appeared superior and failed to listen to the parents. Conflict is felt because the two parties are not working together.
2. Education System (11, 16)	Parent's (and child) are caught in conflict between different programs. Feel in conflict themselves with school personnel who lack understanding and fail to communicate with parents.
3. Elected Officials (17, 18)	Conflict continues as parents feel the school board are not addressing their specific needs. Revealing family history in order to explain child's needs is diminishing, especially when met with lack of response.
4. Medical Profession (27)	Doctors ignorance of parents previous struggle (to gain appointment) leads to insensitive remarks. Parent's immediately feel in conflict with him rather the supported by him.

LEARNINGS IN RETROSPECT:

1. Recognition of Wife's Role (9)	Present personal involvement and past discussion have made him aware of his wife's contribution. Is now able to express this as an admission of his own lack of involvement in the past.
2. Father's Involvement: (22)	Feels obliged to become more involved as wife becomes overwhelmed by total involvement.
3. Father's Involvement: - Increased Knowledge (23)	Knowledge gained by attending meetings and talking with others leads to further involvement.
4. Relate to Child's Needs (24)	Is able to relate to child's need for special assistance with language development because of his own past problems. Realises how much more he is now able to participate since he was helped to overcome his illiteracy.
5. Father's Involvement - by Chance (25)	Opportunity to become involved was not actively solicited but occurred by chance due to wife's illness. Now sees this event as fortuitous.

6. Personal Growth (26, 29, 31, 32)	Involvement has allowed opportunity to examine own feelings and reactions. Now sees the personal growth which he has experienced since he started going to meetings and doing things for his child. This, in turn, is leading to an advocacy role for other father's, and the intention to attempt to learn his child's communication system.
7. Communication Skills (28)	Now realises that getting mad is not enough to effect change. Knowledge and the ability to express yourself are his recipe for communicating your needs.
8. Understanding (30)	Involvement and personal growth have led to a greater understanding of the needs of all deaf children.

Eric's Experience - Written Summary

Eric's experience as Claire's father is characterized by the fiesty and emotional way in which he speaks about the problems that he and his wife have had as they have struggled to understand their child's problems and to obtain medical and educational services which they felt were necessary for her to reach her potential. His frustration and bitterness are evident as he tells of the experience with medical personnel in the pre-diagnostic and diagnostic period. These emotions have continued as the family has moved into the post-diagnostic period and experienced conflict when dealing with educational personnel as they search for early childhood services and schooling for their child. When Eric speaks of the present his increased knowledge, communication skills and subsequent empowerment are clearly evident in his desire and ability to share his experiences with others.

Strong feelings of frustration ..."began when we found out Claire was deaf". Before that diagnosis was made Eric was frustrated because he felt that the doctor "...didn't have a clue". Eric adds that: "He wouldn't admit it, that he didn't have a clue". As he and his wife searched for someone to explain why their child was not babbling and making sounds like other children , Eric explained his own history of being a slow learner in school. When the doctor suggested that Claire had similar problems Eric was resentful that the doctor did not use his expertise and training to see beyond Eric's history and look at Claire herself. He feels that doctors "...always have to make some kind of front...some kind of statement".

Years later, when Claire is doing well in school, Eric still harbours resentment towards the medical profession. His inability to communicate with "so many professionals that aren't really professionals and what they think they are", reveals the sense of cynicism that he experienced as he failed to get answers to his questions. ("They have only got a title...I figure they are professionals because they have that title...I was a little naive and thinking that the professional knew what he was doing "). A sense of disempowerment is evident as Eric senses that the doctor treated him as an inferior rather than listened to him as a concerned father.

Eric's lack of scientific knowledge increases his sense of disempowerment and contributes to his inability to communicate with the doctor. Eric thinks that if the doctor had listened to him and his wife they would have avoided "all the red tape you have to go through to get your child tested because they didn't listen". He tried to communicate his feelings to the doctor as he "argued with him" experiencing frustration because "(he) didn't know what to argue with him because (he) didn't know (him)self". Eric speaks as a frightened parent when he says: "...you don't know what to ask or how to ask it...because you don't have that, you don't perceive to know what is wrong with your child...you just...there's something wrong." The same feeling of disempowerment is evident when Eric talks about later experiences with medical and educational personnel: ("You're really not in a position to tell professionals what they are and what they're not doing").

"What took you so long to get your child in here", was the remark made by a member of the medical profession when after many appointments and much struggle to obtain a diagnosis for Claire's problems she was finally taken to that hospital. The insensitivity of that remark is evident in the way Eric repeats it verbatim several years later. It epitomises much of his frustration and lack of communication with the medical profession.

When the diagnosis of deafness was finally made Eric was faced with an entirely new situation and felt overwhelmed by his lack of medical knowledge. At that time he was working long hours which he now sees as a way of avoiding having to come to terms with what had to be done for Claire: ("I guess I was more or less burying myself in a lot of involvement of what I had to do around myself to...not think about how it was going to be with Claire's future"). This was not a deliberate avoidance, he was doing it "not consciously".

Frustration and an inability to communicate concerns about their child's needs led to conflict with the educational system as Eric and his wife "..had to fight ...because they (the school) didn't understand what we were trying to achieve." The frustration continues with elected officials: "You can't argue with these people because they have to answer to so many people because of public funds". Eric feels it was "because they don't have factual information coming at them." He continues: "I don't feel they make a very good job of researching what they're making decisions on". He relates how he has tried to communicate some of those facts but that it is "frustrating, its difficult, its time consuming...it was really frustrating to always have to spell out your life to somebody else or what they're doing to you".

When Claire was younger and Eric was working many over-time hours the main task of finding and maintaining services for Claire was done by his wife. Recently she has had to remove herself from her previous total involvement because "she found it really overwhelming". Eric recognizes that he has not been involved in the past and now goes "to all the meetings". He feels that he "can't just let Janice do everything" while he "just provide(s) for the home". The impetus that gave

Eric the opportunity for his increased involvement happened by chance. His wife was to be on a panel of parents talking about their hearing impaired children. However, she was sick so Eric attended the meeting as her substitute. In his words he "wasn't supposed to be there". It was a pivotal experience for him. He had never been asked about his feelings or experiences before and he "broke up". He said that: "when it came to me I was choked up...because it brought back all the frustrations and everything else that I've gone through in years dealing with these professionals". He was surpized by emotions which he "didn't even expect".

He now attends most of the meetings regarding Claire's education and is gaining knowledge and confidence from the experience. He said that: "At the beginning you're like a sponge...you're taking everything in...and now I try to size the information and you grow on that". With this new knowledge comes a better understanding of how to communicate effectively. He exhibits a better sense of control and less conflict. He now realizes that in order to be effective he has to "say it right...you can't be mad, you can't be upset".

Eric is now aware of the extra effort required by the family with a deaf child. He feels that the responsibility for gaining services lies with parents who have to "do it right if (they) want to achieve something", because "you can't depend on educators to educate your child". The importance of being actively involved with all aspects of his child's development is becoming clear to him. He now tells other fathers that "you gotta make time...if you want to be involved and get involved...you have to do what you can, when you can...providing the child with experiences no matter what you are doing". When asked what advice he wanted to pass on to other fathers he said succinctly: "Be involved". His own recent involvement certainly appears to have empowered him and enabled him to understand and come to terms with Claire's deafness.

JOE

Introductory Notes

Joe is the father of four children. The oldest child is Jason who has a profound hearing loss in both ears. Both Joe and his wife have normal hearing. It was thought initially that Jason was the only hearing impaired child in the family but subsequently another relative has been diagnosed with a hearing impairment.

Jason was born in a small Albertan community. The family moved to the city when he was three years old in order to obtain medical and educational services for him. Prior to the move they had been relying on their own resources and limited assistance from the local health unit. During the diagnostic period they had to travel to the city in order to access specialist services.

Joe is employed in a management level position and carries some of the stress of his work home to the family. His wife has worked intermittently since Jason's birth and has been the parent most responsible for meeting Jason's medical and educational needs. Because he works a basic nine-to-five day with only limited opportunity for time off work Joe has been content, in the past, to let his wife take that role.

Joe and his wife decided that Jason would use sign language. The method they chose was Signed English. English is the language of the home and they were very concerned that Jason should learn good English language skills during his early years. Since his wife was home with Jason or attending Preschool programs with him during the day, she was able to learn to sign at the same rate as Jason. Jason learned quickly and has achieved a high level of proficiency.

Joe did not have the same opportunity to learn. Further, he does not find sign language easy to learn and has not felt able to take the extra time and effort needed to acquire the skill. He has not kept up with the level of sign skills of the rest of the family. During our conversation Joe expressed his awareness of the difficulties that this is causing between himself and his wife and between him and Jason. He is aware of his problems in this area and can talk freely about them. However, he has not yet made any specific plans to overcome his deficiency.

In the past Joe has been involved with support groups for parents with hearing impaired children. He is not involved at this time, but feels that they were of value to him and wishes that other father's were more interested. If he felt there was more support he would become involved again. However, even in those parent groups Joe admits that he had little chance to talk directly to other father's about their experiences. This is something which he regrets.

Jason is progressing well in school and while Joe attends meetings to discuss his son's progress and needs, he is content to let his wife carry most of the load in that area. He is supportive of her efforts and is quick to give her credit for the work she has done with Jason.

Significant statements from Joe's transcribed interview are organized into thematic abstractions in the following two tables. (Table 6 and Table 7).

Table 6

Thematic Abstractions of Joe's Experience

Excerpts from Transcribed Interview	Two levels of Abstraction 1. Paraphrases	 2 . Themes
J1: We were late picking that up and also since he was a first child.	Takes parental responsibility for not recognizing his child's symptoms. Feels this is partly excusable due to lack of previous experience with babies and their development.	Frustrated by own lack of knowledge
J2: He was thirteen months before he was finally diagnosed as being deaf.	Is upset by the lost time before a diagnosis was made.	Trauma
J3: He finally got his aids when he was 16 or 18 months old.	Exasperated by the delay between diagnosis and receiving the hearing aids.	Frustrated by slow reaction of medical personnel
J4: The doctor just walks out and throws at us...by the way he's got CP and walks out the door.	Resentful of what he sees as the callous and unfeeling way the doctor imparted information.	Resentful of medical lack of sensitivity
J5: Nothing really sinks in when, you know, when the child is first diagnosed.	Is disempowered and emotionally stunned by the diagnosis.	Trauma of the diagnostic process
J6: You can't associate the terms moderate and profound...it doesn't really mean anything	Lack of specialized knowledge makes him feel inferior - unable to cope with the medical terms. They were meaningless to him at that time.	Intimidated by medical jargon. Feeling of powerlessnes s

J7: Its always been someone elses child that had the problem.	Surprised by something that he never expected to happen to him and his family.	Despair at diagnosis
J8: It wasn't easy. That first year was not easy.	Remembers all the difficult adjustments that had to be made in the first year.	Struggle
J9: I was there for most of the...whenever they told us anything new about him.	Tried to attend most medical appointments but realises that his wife was there all the time.	Awareness of wife's greater involvement
J10: A lot of those trips were made alone which was not easy for her (wife), because I just couldn't get that much time off. (When she got all this information in the city)...it didn't feel good that I wasn't there to support her. Everything, all the uh, the whole burden is on her then.	Expresses regret that he was not able to attend all appointments because of work committments. Feels pulled by two loyalties - need to provide for his family emotionally & financially. Experiences negative emotions because he could not support his wife.	Recognizes wife's role. Conflict between family & work.
J11: She'd come home and say well let me see, what did they tell me? Was it this or was it that, I can't remember. Because when you first hear it, it sort of bowls right over you. I remember Kathy trying to remember what they told her one day...that's when I wished I could have been there myself to get it first hand. Between the two of us I think we would have been able to patch it together.	Difficulty of trying to understand his child's problems is increased by having to rely on his wife to pass on information.	Conflict between work & child.
J12: She was there. Why didn't she write it down? I remember thinking some of those things, why didn't she write it down so she'd come back home and have it all straight.	Guilt at not being able to be present at appointments is expressed as frustration with his wife for not being able to remember information.	Marital conflict
J13: I suppose we block it to a degree but partly I think you feel like an idiot sitting there with a notepad - Excuse me Doctor, could you say that again.	Feels intimidated by medical profession and information.	Communic-ation/ Frustration

J14: Your mind's just sick of thinking about things. About the future and what we can do and how we can do it.	Continual anxiety about how to help his child and about future needs.	Anxiety about the future
J15: I guess you don't realise that there is so much going on...so many fears to put up with.	Overwhelmed by lack of knowledge about deafness and the future.	Anxiety & fear
J16: We wanted him to have good language skills. It wouldn't be spoken language but at least good english skills, you know, written, reading, writing.	Aware of the importance of good language skills for his child.	Positive goal for child
J17: We labelled everything...all over the house. We decided to put all the endings on the words right now...conjugate the verbs, stuff like that...and if he sees it right off...he's brought up with it and he knows how people talk.	Remembers total family and house involvement in providing linguistic opportunity for child.	Accomm-odates family lifestyle
J18: I think one of the reasons he has such good language now is because of the time Kathy spent with him.	Recognizes the time and effort made by his wife.	Father's recognition of Mother's role
J19: (Wife's sign skills) Way ahead, Yeah! I'm way behind. Jason just looses me now. (His sister) can understand him much better than I can...lately he gets a lot more frustrated if I don't get it the first time around. They (the rest of the family) see it a lot more. They're with him during the day.	Admits his lack of sign skills and inability to communicate with his son. Sees it as a result of being at work all day rather than an inability to commit himself to learn sign.	Recognises his avoidance of learning sign language
J20: (Experiences with the medical profession.) Some of those wern't the best.	Remembers negative experiences with medical personnel.	Frustration with medical personnel
J21: I remember sitting there and we'd talked about it on the way in and we knew there was something wrong. We just didn't know how bad it was. And when they came in and said, you know, he's moderately to severely profound...like we didn't realise it was that bad.	Despite prior feelings that something is wrong with his child he is shaken by the diagnosis.	Trauma surrounding diagnosis

J22: Mind you we can't really remember what else they told us. All you can think of is that my kid's deaf. And now we can see why. A lot of times, you know, some of the parents get told a lot of things by the professionals that first day, and then they come back later and say, you never told me this and you never told me that - and I can see why.	Parents are overwhelmed by the situation and the diagnosis and unable to retain information.	Trauma of diagnosis of deafness
J23: I remember thinking, God is it that bad. That's one thing I do remember	Experiences strong emotion at diagnosis.	Trauma of diagnosis of deafness
J24: We realized that Jason was not getting the vocabulary he needed. Nothing against them(school program) but that's not what we wanted. Like that program is fine for other kids.	Parents have very clear goals for their child when selecting educational programs.	Involvement in child's educational program
J25: They have all these clinics and then they haul you in and give you all the results and its just, you're so scared sitting there with the walls.	Anxiety for child is increased by feelings of insecurity in a strange place.	Fear of medical bureaucracy
J26: I think most of the decisions we made we made them together.	Feels that he has been involved in major decision making for his child.	Family involvement
J27: Experiences with educators (have been) frustrating. A lot of teacher's don't have a clue what a hearing impairment is...they just don't know what it involves.	Is frustrated because everyone does not possess the specialized knowledge necessary for his child's education.	Frustrated with educational personnel
J28: ...a lot of meetings...some of them you just finally give up. I sat in on a couple of meetings. Kathy would break down...basically they just sat there...Oh poor woman, she's going to break down again. That's the feeling I had of the people at the meeting...thinking, Oh just get out of my hair...that sort of thing.	In advocating specific services for their child, experiences lack of sensitivity to his wife's emotions by educational personnel.	Frustrated with educational personnel

J29: ...language barrier. He's far ahead in words and I have trouble reading some...when it comes to reception my skills are very, very poor.	Admits his inferior sign skills and difficulty in communicating with his son.	Communic-ation
J30: Kathy keeps giving me hell that I've got to get better at signing.	His poor sign skills are a source of disagreement.	Marital conflict
J31: I know a lot of times he'll go ask her something to ask me and I can be sitting right here. That's when I realise my signing skills are not too good. It doesn't feel good, that's for sure...and its getting worse to as his signing progresses, its going to keep getting worse.	Feels disconnected from his family because of his limited sign language but is not motivated to improve. Avoids making a committment to improve.	Communic-ation/ Avoidance
J32: Its getting better you know...I'm picking it up slowly. I stayed with him for a week and just that week of being with him constantly really helped...just because I was there for the whole day.	Despite lack of committment to improve sign skills knows that they improved when he was forced by circumstances to communicate with his son.	Communic-ation/ Avoidance
J33: I come home from work...and had a day at work and I just don't feel like sitting there learning more sign language. Its the last thing I want.	Feels drained at the end of a working day and not able to make the extra effort to learn his sons language.	Communic-ation/ Avoidance
J34: I sure would like the educational system to be a lot more understanding. They seem to bucket them (special needs children) all together.	Resents educational personnel for their lack of awareness of his son's specialized needs.	Frustrated with educational personnel
J35: The only thing we really worry about is the social aspect of it.	Concerned about his son's possible social isolation.	Anxiety for the future
J36: That's the one thing we tried to keep...instill in him. Self-esteem, self confidence. Like, if you think you can do it - go ahead and do it.	Expresses the importance of good self-esteem for his child.	Awareness of need for good self-esteem

J37: But we've heard...a lot of older deaf adults say that they resent their parents.	He worries about the programs that he and his wife are providing for his son in their struggle to provide a sound education for him will they be alienating him from the deaf community/ themselves?	Anxiety about the future
J38: We want him to be self sufficient when he grows up.	Has a strong desire to provide his child with the ability to be independent.	Anxiety about the future
J39: (Advice to other fathers) Stay involved! Don't let your wife do it all.	Acknowledges the greater involvement by his wife and the alienation that he has felt because of his lesser involvement.. Also recognizes the strength that he has gained from that involvement.	Conflict between work & child/ marital conflict
J40: That's really helped me too (being involved in a parent society). There wern't that many fathers, there were some but they were always the same ones. That's why I keep wondering how much support some of the other mothers are getting.	Sees his involvement in parent associations as a way of supporting his wife as well as a source of self growth.	Father's involvement
J41: I think a big part of it is that some of the fathers havn't accepted it. I think some of them have a harder time to accept it than the mothers.	Sees father's lack of involvement as lack of acceptance of the deafness. Feels that Fathers may find the child's deafness harder to accept than mothers do.	Acceptance of child's deafness
J42: When we first found out that Jason was deaf we talked about it. We decided there's nothing you can do. We can't change it. He's deaf and thats all there is to it. Lets get on with it. What can we do for him? So I think the grieving part didn't last that long.	Feels that he and his wife accepted Jason's deafness soon after the diagnosis. having accepted it , they were able to make strong plans and goals for him.	Acceptance of child's deafness

J43: A lot of deaf kids could go a lot further if they had more support...it keeps going back to their english...language skills. For so many of these kids their education stops right there at 3:30 with the school bell.	Deaf children need support from both home & school if they are to develop linguistic proficiency. Feels they need more support from home.	Family involvement in language development

Table 7

Higher Order Thematic Description of Joe's Experience

Thematic Clusters	Generalized Descriptions
FEARS:	
1. The Future (Excerpts from Table 6: 14, 15)	Worries about what the future will bring for his child, what demands will be made of the family and how they will cope.
2. Social/Emotional Development of Child (35, 37, 38)	Concerned that child will fit into society and value his own self-worth.
3. Medical Bureaucracy (25)	Ignorance of medical personnel & procedures, combined with fears about the diagnosis combine to make him feel insecure & overwhelmed.
TRAUMA:	
1. Diagnostic Process (4, 5, 20)	Memories of the diagnostic process are characterized by negative feelings toward medical personnel. He still feels resentment for the doctor's lack of sensitivity to the parents feelings and struggles.
2. Diagnosis of Deafness (7, 2, 23)	Despair is deepened when the diagnosis of deafness is confirmed and he realizes that things will never be 'normal' for his family. Trauma is intensified by his inability to either understand or absorb the factual information given at that time. This period was a time of bewilderment and negative emotions.
3. Disempowerment (6, 22)	Feels overwhelmed by the diagnosis and in a situation where he is unable to retain or understand given information.
4. Communication with Medical Personnel (13)	Finds communication with medical personnel difficult because of the personal nature of the subject and because he feels intimidated by his lack of knowledge.
5. Struggle (8)	Memories of the first year of his son's life are filled with seemingly endless problems related first to anxieties and secondly to the overwhelming time of diagnosis.

6. Frustration (1, 2, 3)	Lack of knowledge about deafness and his son's needs cause frustration before, during and after diagnosis.
7. Frustration with Educational Personnel (27, 28, 34)	Meetings with educational personnel are difficult as the parent's try to gain a say in their child's needs. Teacher's with specialized training resent parent's close involvement in determining programming for their child. Frustration is also felt in the opposite situation where classroom teachers do not possess the specialized knowledge necessary to help the hearing impaired child.

CONFLICT:

1. Communication (29)	Experiences difficulty in communicating with his own child. Sees this as a barrier between them which he realizes he must surmount but is yet unable to do so.
2. Avoidance (19, 31, 32, 33)	Admits that he needs to make a deliberate effort to learn sign language in order to catch up with his son's linguistic skills. Realizes that his skills improved when he was forced by family circumstance to spend more time than usual at home all day. Expresses his feelings of tiredness at the end of a working day with no extra energy to learn sign language in the evening. Sees this as the reason for his lack of ability rather than lack of commitment. Is in a state of cognitive dissonance.
3. Conflict Between Child & Work (10, 11, 39)	Realizes that he has not been able to attend as many appointments as his wife and expresses the anxiety he feels as he is pulled between the two commitments.
4. Marital Conflict (12, 30)	Some conflict is covert and not expressed to his wife. e.g. Feeling that if he had been present they could have done a better job of understanding what the doctor had said. Other conflict is overt. e.g. His lack of sign skills "Kathy keeps giving me hell!".

INVOLVEMENT:

1. Awareness of Wife's Greater Involvement (9)	Recognizes that his wife has played a greater role in his son's development. Feels some anxiety that his own role has not been as great but is quick to praise his wife for what she has done.

2. Education (16, 24)	He & his wife have very clear goals of what they expect from the education system for their child. They have had to be more involved than is usual for parents in order to gain service for their child.
3. Family (26, 43)	Despite his inability to attend all meetings and commit himself to learning sign language feels that he has been involved with all the major decisions which have been made for his child.

RETROSPECTIVE LEARNING:

1. Accommodates Family Lifestyle (17)	Total involvement and commitment of family to language learning has been a strong positive influence for his child's educational and linguistic ability.
2. Father's Recognition of Mother's Role (18)	Recognizes that most of that positive influence has come from his wife's involvement.
3. Self Esteem (36)	He is aware of the importance of good self esteem for his child. This concerns him whenever parental decisions are made concerning his child's future.
4. Father's Involvement (40)	Recognizes the personal support which he received from his involvement in a parent group but regrets that more father's are not involved.
5. Acceptance (41, 42)	Sees other father's lack of participation in parent groups as an indication that they have not fully accepted their child's deafness. Is proud that he and his wife both took the positive attitude to find out what they could do to help their child develop to his full potential.

Joe's Experience - Written Summary

Joe's experiences as the father of a hearing impaired son are characterized in the early stages, when the family first becomes aware of differences in his development, by fear. As Joe and his wife struggled to find medical support and a diagnosis for their son, trauma and conflict are evident. Trauma and conflict continue as the focus of the child's needs changes from medical to educational services. With involvement and time, Joe's reminisences are coloured by retrospective learning which exemplifies his personal growth. However, fear for his child's future never diminishes and is an ever-present emotion.

Memories of the first year of Jason's life are not easy for Joe to relate: "It wasn't easy. That first year was not easy". Jason's birth was not straightforward, necessitating an immediate airlift to a major hospital many miles from his home. The fear began immediately following Jason's birth. At it was for the baby's life and later it was for his son's future. "They have all these clinics" said Joe as he remembers being treated with a lack of sensitivity. ("They haul you in and give you all the results..."). Despite his wife's presence, his extreme sense of isolation at that time is evident in his narrative: "...You're so scared sitting there with the walls". After the diagnosis of profound deafness was made, the fear continued as

Joe tried to make sense of all the information he received and to make it apply to Jason's individual needs. For Joe, "There is so much going on...so many fears to put up with. This fear continues today as Joe worries about "...the social aspect" of Jason's development.

Resentment, expressed by deaf adults, towards the oral education imposed on them by their parents, makes it more difficult for Joe and his wife to do what they feel is in Jason's best interests. They strongly feel that the acquisition of good English language skills is imperative for Jason in order for him to actualize his choices when he is older. Joe's statement that: "We want him to be self-sufficient when he grows up" is a normal aspiration for parents, but for Jason's family that goal involves continual work, stress and anxiety.

The stress is exemplified by old memories as well as by present worries. Joe is still resentful of the doctor who "...just walks out and throws at us" the diagnosis. The traumatic feelings experienced at that time are still fresh in Joe's mind. "I remember thinking, God is it that bad. That's one thing I do remember". He states that "nothing really sinks in when, you know, when the child is first diagnosed". Joe's lack of specialized knowledge combined with the emotional involvement with his child lead to feelings of inferiority. ("You can't associate the terms moderate and profound...it doesn't really mean anything "). Time and experience have relieved some of the trauma for Joe. He now understands why he felt so powerless and recognizes that it is a normal reaction in such circumstances. The wisdom of hindsight is evident as he remembers the time of diagnosis and the certain knowledge of his son's deafness. Now he can see why he was so overwhelmed. ("A lot of times, you know, some of the parents get told a lot of things by the professionals that first day, and then they come back later and say, you never told me this...and I can see why"). However, his use of words such as "...throws at us" and "...haul you in" indicate an enduring resentment toward medical personnel.

When asked about advice to other fathers which he would like to pass on from his own experience Joe said, without hesitation, "Stay involved! Don't let your wife do it all". While Joe has been involved he is aware of his wife's greater involvement. His statement that: "I was there for most of the (time)...whenever they told us anything new about him", indicates that Joe is aware of times when he was not there to hear things first hand and to support his wife. Guilt for not being present became a conflict between Joe and his wife when she was unable to remember exactly what she had been told by medical personnel. Joe remembers thinking, "Why didn't she write it down so she'd come back home and have it all straight"?

A continuing personal stress for Joe and another cause of marital conflict is Joe's lack of sign language skills. He comments: "Kathy keeps giving me hell that I've got to get better at signing". He has some rudimentary sign skills but has not achieved his son's level of proficiency. This also contributes to an increasing sense of isolation as he is unable to communicate effectively with Jason. Joe lacks Jason's vocabulary and has difficulty interpreting sign. ("He's far ahead in words and I have trouble reading some"). He admits his deficiency, acknowledging that his reception skills are "very very poor". Despite frequent reminders, for example when his son will "go ask her (his wife) something to ask me and I can be sitting right here", Joe still appears to be avoiding making the commitment necessary to become more involved in his son's life. He feels drained and stressed by other problems at the end of his day at work and "...just doesn't feel like sitting there learning more sign language". He stresses this feeling as being "the last thing I want".

Joe has been actively involved with parent support groups and has found that they have "really helped" him. He wonders if the inability of some father's to participate in such groups is because "...they have not accepted it". He thinks that,

"...some of them have a harder time to accept it than the mothers" though he doesn't elaborate on that thought. His own acceptance came soon after the diagnosis when he and his wife "decided there's nothing you can do...he's deaf and that's all there is to it". They turned their thoughts to the question: "What can we do for him"?

Table 8

Synopsis of Themes

1. Fears:	Fear of the Unknown, of the stigma of deafness, of the diagnostic process and of the future.
2. Frustration:	Frustration with the "system", medical 7 educational bureaucracy. Frustartion is experienced in determining a communication system, implementing & learning the method, and in communication difficulties between parent & child.
3. Trauma	Trauma is present before, during & after ,the diagnostic process. Despair, disempowerment, a sense of being overwhelmed are all experienced as the father interacts with medical & educational personnel. Struggle with the "system" and with the needs of the deaf child all lead to personal & family stress.
4. Conflict	Conflict occurs at various levels and a variety of situations. It is experienced within the family between the parents and in choices which have to be made between work & family commitments and between career & child's needs. It is experienced outside the family as members interact with medical & educational personnel & with elected officials.
5. Retrospective Learining	Father's exhibit retrospective learning in several ways. In their recognition of their wife's role, of volunteer service, of the possibility of interaction with their child, and of the accommodations which need to be made to their lives and future plans. Involvement has led to personal growth, the development of self-esteem, and a greater acceptance of the child's deafness and the family present situation - "The battle is not hopeless".

6. Involvement	Involvement with deaf child and his/her needs leads to awareness of wife's contribution and of the educational needs of the child. It also develops an awareness of the child's & the family's future.

Table 9

Higher Abstraction of Clustered Common Themes

	(Numbers from Table 8)
1. Encounter with a New and Unexpected Experience	1. Fear 2. Frustration 3. Trauma 4. Conflict
2. Integration of New Experience Leads to Personal Growth and Increased Acceptance of Child's Deafness.	5. Retrospective Learning 6. Involvement

CHAPTER V

DISCUSSION AND IMPLICATIONS

A Written Synthesis of the Fathers' Experiences

Table 9 delineates two higher abstractions of the clustered common themes. The first higher abstraction is the encounter with a new and unexpected experience and the second, the integration of new experiences leading to personal growth and increased acceptance of a child's deafness. This written synthesis of the experiences of the three fathers is organized under the headings of the clustered common themes which have been grouped together in the higher level abstractions in order to clarify the synthesis for the reader.

1. Encounter with an Unexpected Experience

The clustered common themes that constitute this higher level abstraction are fear, frustration, trauma and conflict.

Fear

Fear is an emotion expressed by all the coresearchers. It is the strongest feeling of both Bart and Joe when they speak of the pre-diagnostic and diagnostic period of their children's deafness. When Bart says, "Everyone's afraid of the unknown" he epitomises this time for him and Joe. Bart expresses the most fear. His lack of knowledge about deafness and deaf people, combined with past negative experiences, cause him to see deafness as a stigma, something to be feared. His fear arose as he became intimidated by medical and educational personnel who were supposedly helping his family. The diagnostic process with all its appointments and meetings with strangers, emphasised the fact that there really was something wrong with Sarah and the time involved in waiting for a diagnosis increased the tension. The future also holds fear as Bart struggles with seemingly endless educational decisions. Fear of the future is emphasised by his feelings of alienation from the deaf community though he suspects that is with them that his child may feel the most comfortable.

Likewise for Joe, the deaf community created feelings of fear as he worries about the future social and emotional development of Jason, but the most overwhelming anxiety began as soon as Jason was born because of complications surrounding his birth. The fear continued as he experienced lack of sensitivity from medical personnel. His use of words and phrases such as "..they haul you in" and "...you're so scared sitting there with the walls" and "...so many fears to put up with" eloquently express his fear during the diagnostic period.

Eric's fear is more focused on the future. His anxiety about the deaf community and how it will affect Claire's relationship with her family. He sees hearing people as normal, "We wanted Claire to have hearing children's mannerisms and just to be as normal as could be", and deaf people and schools as different and alien, something to be afraid of ("...it (a deaf school) just didn't sit right with me"). His ignorance of the deaf community makes him see them as a threat to the future relationship between his daughter and the family. He is concerned for her future social and emotional development and about how she will fit into society. He feels there is no place for him though his expressed fear indicates that he knows there will be a place for her.

Frustration

Eric's more fiesty personality led to frustration rather than fear during the pre-diagnostic and diagnostic periods. Frustration with a "system" (educational and medical) of which he was ignorant and which he did not perceive as helping him to assist his daughter, encompassed his early experience with his daughter's deafness. He harbors resentment against members of the medical profession because he sees them as the cause of his frustration. Now, years after his daughter's diagnosis, Eric continues to speak with bitterness: "I was a little naive and thinking that the professional knew what he was doing." His frustration is not just with medical personnel but with educators too. His greatest frustration was with professionals with whom he did not feel any rapport ("...he (the doctor) didn't have a clue. He wouldn't admit that he didn't have a clue...always have to make some kind of front...some kind of statement").

Bart also experienced frustration when dealing with medical bureaucracy. His frustration was with doctors when he did not see them reacting to parental concerns, with questions which were not being answered and unasked questions which he felt were not being explored. His frustration today is with his inability to communicate well with Sarah ,and with continuing educational concerns.

Trauma

Frustration is present in Joe's experience too but it is encompassed within the thematic cluster of trauma. For him the pre-diagnostic and diagnostic periods were felt as trauma. Despair during the diagnostic period is intensified by his inability to understand and consequently absorb the plethora of factual information he was given at that time. This, combined with seemingly endless problems and struggle, led to feelings of disempowerment. His lack of knowledge about deafness and Jason's needs caused him frustration before, during and after diagnosis. Today his chief frustration is with educational personnel as the family attempt to have closer involvement in Jason's educational program. This has caused resentment from trained specialists. Conversely, Joe experiences frustration with classroom teachers who do not possess specialised knowledge. This is a Catch-22 situation for Joe as he attempts to become more involved in Jason's life and to understand his educational needs.

The most traumatic period for Bart was during the time that Sarah's deafness was diagnosed. The shock of the diagnosis, delivered in unfamiliar surroundings, rendered him unable to react in any normal manner. This is an understandable situation, but one which was very traumatic for Bart. Even though he had some personal experience with medical institutions, his experiences of the medical appointments and personnel involved in the diagnosis left him feeling disempowered. Once his fears were confirmed and he was told that Sarah was deaf he experienced despair. The trauma was so great for Bart that he avoided close involvement with Sarah's special needs, leaving such things as speech training, daily driving, reading to expand knowledge and gain understanding of deafness, to his wife. After the diagnosis was made the initial attempts to learn all the new techniques caused an overwhelming stress for the family.

Conflict

Bart's confrontational personality and his experience of running his own business lead him to expect to be in control of his life. When faced with Sarah's problems and the ensuing interaction with medical and educational bureaucracy, he found himself in conflict. He resented having to "fight" for support services for his child. The ongoing explanations, repetitions of family history, making continual requests for service left him feeling that the "system" was against him rather than there to help. He felt unable to adjust his lifestyle and career in order to accommodate Sarah's needs. These pressures led to confrontation and conflict with his wife. When threatened with the disintegration of his family if he refused to move, he capitulated and made the necessary moves. But, it changed him from an outgoing, socially involved person to a homebody. Bart speaks nostalgically of his past life before Sarah was born. He does not regret any of the moves that he made but the nostalgic tone indicates a battle, or a dream, lost!

The medical appointments during the pre-diagnostic time and diagnosis of Claire's hearing loss, caused feelings of conflict for Eric and his wife. Eric still relates, verbatim, insensitive remarks made by medical personnel during that period. He feels that they were in conflict with the very people to whom they looked for support and assistance. Similar feelings of conflict were expressed by Eric when he told of meetings with educators and elected officials as services are sought for Claire.

For Joe the medical appointments engendered family conflict. As a result of feeling guilty about not attending Jason's medical appointments Joe would displace his guilt in the form of resentment toward his wife, when she was unable to relate exactly what the medical personnel had told her. Not self-employed and therefore unable to take much time away from his work to attend medical and educational meetings, Joe experienced conflict between his role as a father and as a provider - conflict between the demands of his child's needs and his work. One of Jason's continuing needs is to use sign language to supplement his oral and listening skills. Joe has not been able to commit himself to learning sign language and appears to be in a state of cognitive dissonance as he justifies his lack of commitment by pleading fatigue at the end of a working day.

Involvement with medical personnel was a major source of conflict for all the father's though it affected them in different ways. For Bart and Eric the conflict was of a confrontational nature with the personnel themselves. For Joe the conflict was more internalized as he felt pulled between various commitments.

2. Integration of New Experiences Leading to Personal Growth and Increased Acceptance of a Child's Deafness

The clustered common themes that constitute this higher level abstraction are involvement and retrospective learning.

Involvement

All the fathers acknowledge that their wife's involvement has been greater than their own and they all recognize that this effort and commitment has given the children a strong foundation for learning. Similarly, all the fathers are now more involved than they have been in the past, being obliged to take over a role previously filled by their wives. The wives are all moving on to other activities because of an expressed need to distance themselves from previous total involvement which they now find overwhelming.

For Eric, increased involvement began by chance when he was forced to attend a meeting because his wife was sick. For Joe, his wife's move to follow career opportunities has necessitated his greater involvement. A similar scenario has forced Bart to spend more time with Sarah, a situation which he now finds rewarding. Despite his past feelings of conflict between work and child needs Joe has always felt involved at the decision making level and he and his wife have always had strong and clear goals for Jason.

When asked for any advice which they would like to pass on to other fathers, the necessity of being involved with their child's educational, medical, social and emotional needs was recommended by all three co-researchers. Joe's words epitomize their feelings, "Stay involved! Don't let your wife do it all".

Retrospective Learning

In retrospect Joe also acknowledged the support that he has gained from being involved in a parent group. He feels that the strong commitment of the family to language learning has been a strong positive influence on Jason's educational and linguistic ability.

Being able to recognize and praise his wife's continuous commitment has enabled Eric to admit his own shortcomings and lack of involvement in the past. The knowledge which he has gained from attending meetings and talking with others about his deaf daughter have given him increased self confidence. The personal growth, increased knowledge, improved literacy skills and a sense of assurance which involvement has engendered for him has allowed him to move into an advocacy role for other fathers, and a renewed commitment to improve his communication with Claire. He now realizes that getting upset with the system is not enough to effect change. Knowledge of the topic under investigation and the ability to express oneself are his recipe for good communication.

Because of his desire and need to be involved with Sarah's life, Bart can now see the need to be involved as early as posssible with a child's special needs. He also sees the necessity of staying involved. He is now resigned to changes and accommodations which he has made in the past and ready to make others in the future, if they are needed. His acceptance of Sarah's deafness has come after a long personal struggle but it has led him to positive thoughts for Sarah's future. Like the other fathers, discussion of present commitment allows him to recognize past avoidance.

Relationship of the Experiences of the Coresearchers to the Literature Review

Introduction

The majority of studies in the literature pertaining to hearing impairment fall within the natural science mainstream. Further, the majority of family studies are of the whole family or specific to mothers. This study adds to our knowledge of the experiences of fathers of hearing impaired children. For organizational purposes and to assist in cross reference I have used the same headings in this discussion as those used in the review of the literature in Chapter II of this study. These are: Family Dynamics, Stress, Early Diagnosis, and Early Intervention.

Family Dynamics

That "the greatest impact of deafness is upon the family unit and the relationship of its members" (Morgan, 1987, p.48) is supported by the experiences of Bart, Eric and Joe. Bart's personal struggle to relinquish a way of living in which he felt comfortable and fulfilled, the severe impact that this had on his marriage, and the family's subsequent move to a larger centre for his daughter's medical and educational services, epitomize Morgan's statement. In a different way, the small resentments which Joe related about his inability to learn sign language as easily as other family members, and the feelings of alienation engendered by his attempts to understand the doctors recommendations from his wife's retelling of medical appointments that he was unable to attend, exemplify the stresses and strains which existed in his family at that time.

For Eric, the impact of his daughter's deafness had some positive effects. He spoke of his improved literacy skills, increased self-confidence in meetings and in working to gain service for his daughter and of the knowledge which he has gained from learning how to cope with her hearing impairment.

Some of the findings of the study of mothers of hearing impaired children by Morgan (1987), including personal growth, concern over educational planning and the importance of a fluent method of communication, are all features of the experience of Bart, Eric and Joe.

Similarly, the ways in which a child's handicap may threaten the integrity of a marriage (Featherstone, 1980) namely, the reshaping of family organization, the possibilty of conflict and the creation of strong emotions are all evident in the experiences of the three fathers. The assumption that fathers of hearing impaired children may have different experiences and emotions from mothers is also evident. Bart struggled with the loss of the house which he had built, a selfowned and operated business and community involvement which he enjoyed, at a time when his wife's priorities were more centered on their daughter's needs. Eric exhausted himself working at three jobs in order to distance himself from a situation which he did not understand or feel capable of dealing with. Joe continues to be somewhat separated from his family's day-to-day living because of his inability to learn their new communication system.

Stress

Luterman (1987) writes of the increased level of stress experienced by families of hearing impaired children. This is evidenced by the first higher abstraction of the coresearcher's experience, the encounter with a new and unexpected experience. The clustered common themes of fear, frustration, trauma and conflict are all related to the stress experienced by these fathers and are discussed in more detail at the beginning of Chapter V.

The grieving stages of (1) denial, (2) anger, (3) bargaining, (4) depression, and (5) acceptance (Kubler-Ross, 1969) can all be identified in the experiences of the coresearchers though not in the same linear model. For example, Joe described how very early in his son's life he accepted that there were problems, acceptance did not come at the end of a grieving process. That "the crisis is not in the event but in the response to the event" (Luterman, 1987, p.48) is exemplified by Eric's breakdown when speaking on a panel for other parents years after his son's diagnosis.

Early Diagnosis

The importance of early diagnosis as an important factor for hearing impaired children and their families (Gregory, 1986: Mendelsohn, 1981) and the problems which surround the diagnostic process (Luterman, 1984: Moores, 1982: Shah, Chandler & Dale, 1978) are areas where understanding is still lacking. Bart, Eric and Joe all spoke of stressful experiences surrounding the diagnostic period, and analysis of their experiences revealed feelings of fear, frustration, conflict and trauma at that time.

Early Intervention

The children of all three fathers were involved in early intervention programs when they were young and the mothers and the children appear to have drawn support from such programs. However, the fathers were not actively encouraged to participate. Bart saw the early programming as his wife's responsibility, adding to the inability of the family to work together. Similarly, Eric's wife was trained to work with their son and gained personal knowledge of her son's needs and ways in which she could assist him while Eric submerged himself in work and failed to gain the new knowledge at the same rate. Joe is still struggling with the communication system which his son and wife first learned in early programs and now use with ease.

Implications

It is evident that the findings of previous research on hearing impairment are frequently supported by the experiences of the coresearchers. The value of this study must be that it links such experiences directly with fathers of hearing impaired children and identifies them as family members who need to be included when services are provided for their children.

Analysis of the experiences related by the coresearchers may help to illuminate some of the problems experienced by parents, educators and members of the medical profession as they work together to help deaf children. Focussing on the lived experiences of fathers may add to our overall knowledge and understanding. The intent of this study is to provide insight into the lives of hearing fathers of hearing impaired children within the context of the family. This in turn, could help parents and professionals working with such families.

Looking for meaning in the lived experience of fathers of hearing impaired children may add to our existing knowledge of dynamics within such families and lead to fuller understanding of their needs.

Initial fear of the unknown has now altered for these fathers to fear of a different unknown. Diagnosis is over, deafness is confirmed, the parents have learned some teaching and coping skills, but fear of the unknown is now fear of a future involving career opportunities for deaf children, independence, self esteem and family unity. Relationship with the deaf community is another expressed fear. As long as hearing parents, in this case the fathers, are expressing fear of a social and cultural group who could provide social and emotional and educational support for their deaf children, the provision of this support is not going to be an easy task.

The knowledge and confidence which the coresearchers have gained through living with their hearing impaired children appears to have altered, rather than alleviated, their feelings of fear and apprehension. For example, all the fathers are aware that feelings of alienation from the deaf community and its role in their children's future are something with which they will all have to deal in the coming years. However, no one expressed a need to find out more about the deaf community or to share their fears with them, at this time. There are strong indications of a need for greater understanding and better communication in this area in order to support both the children and their families.

Deafness is not an obscure condition. It is bandied about as a household word, and yet there is a pervasive ignorance about the different ways in which it manifests itself and the effect which it has on the linguistic and social development of young children. Such ignorance is evident in the words of the coresearchers. The clarity with which all the coresearchers related their experiences, even though much of it took place several years ago, indicates the depth of emotion involved and the profound effect that their experiences have had on their lives.

The reader should be cautioned that it is not possible to extrapolate any gender related information from this study because the gender of the children has been altered in order to preserve anomymity. Insight into the ways in which parents relate to the same or opposite gender children may provide interesting questions for a future study. Similarly, the data collected for this study does not give us any insight into the relationship of the fathers with other children in the family. Whether the experience with the deaf child leads to increased or improved parenting skills is also a question for future investigation.

It is not the intent, or even possible, to end this study with a "grand flourish" (Wolcott, 1990). By the same token, this concluding chapter will not tell the reader what ought to be. It is an attempt to analyze and synthesize experience of a particular phenomenon. Fathers are the least acknowledged people in hearing impaired families; mothers and children have been the subjects of many more studies.

It is my hope that as medical and educational personnel working with hearing impaired children and their families become more aware of the needs of those families greater effort will be made to include fathers in all aspects of service for their hearing impaired children.

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Appendix A

DEMOGRAPHIC DATA SHEET

Date: __________

Name of Father: ______________________________

Name of Mother: ______________________________

Address: ______________________________

Postal Code: ____________

Telephone: Home: ___________ Work: ______________

Name and age of all children in the family: ______________
____
____

Do you work outside the home?
Father: Yes __ (full-time __ part-time __) No: __
Mother: Yes __ (full-time __ part-time __) No: __

Do you belong to any groups for families of hearing impaired children?
Yes/No: __ If yes, please specify names of groups and name of member:
____
____
____
____
____
____
____

Age of hearing impaired child: _______

Degree of hearing loss: Right Ear: ______ Left Ear: _______

Cause of hearing loss:

____

Age of onset: ____________________________________

Age at diagnosis: ________________________________

Educational programs attended:

____

____

____

Preferred method of communication:

____

Appendix B

CONSENT FORM

I, ______________________________, agree to participate in the study of fathers of hearing impaired children being conducted by Margaret Kay, for her M.Ed. thesis, under the supervision of Professor J. Osborne. I understand that my interviews will be recorded on audio-tape and the tapes erased when the project is completed in order to guarantee confidentiality. Names, family situation, and details of experience may be changed to ensure anonymity. I further understand that I may terminate my involvement in the study at any time, if I so desire, without prejudice to myself.

____

Signature

____

Date

Appendix C

INFORMATION FOR CORESEARCHERS

I am a qualified teacher of the hearing impaired and am presently working on my thesis as part of the requirements for my M.Ed. degree. After working in the Preschool for the Hearing Impaired at the Glenrose Rehabilitation Hospital in Edmonton, I have been working for Alberta Education as a consultant for the hearing impaired in Northern Alberta, and as an itinerant teacher of the hearing impaired for the Grande Prairie School District. I have been substituting for a person on leave of absence. He is returning in September and I will then be teaching a preschool group for the hearing impaired at Crystal Park School in Grande Prairie.

I am also the mother of three children aged nineteen, fifteen and nine. Mike, the oldest, has a severe to profound hearing loss caused by congenital rubella. He uses oral communication and will be completing his Grade 12 at Strathcona Composite High School in the 1990/91 school year.

My thesis is to be an existential-phenomenological study of the experiences of fathers of hearing impaired children. The question which my research will address is: <u>What is it like to be the father of a hearing impaired child?</u> A secondary question will be: How are the experiences of the father similar to, or different from, those of the mother?

In order to gather data, I am asking parents of hearing impaired children to join me in relating our experiences. Rather than observing, collecting numbers and drawing inferences, I am gathering information from people who have had the "lived experience". Our conversation will be recorded on audio-tape and then transcribed. A thematic analysis will attempt to reveal common essences and structures. When this is complete I will ask you to read the analysis to see if i have accurately described your experience.

The study will involve five couples who are the parents of a hearing impaired child. Since the description of their experience will provide the data for this study they will be referred to as my coresearchers. The interviews will take place in a mutually agreed upon place where the co-researchers feel the most comfortable. I intend to talk with each father and mother separately for about one hour each, and then the couple together for a further half hour.

I am not interested in specific incidents, professionals or programs but in your lived experience with your hearing impaired child. Try to relate your thoughts, feelings, emotions, criticisms (good and bad), and your hopes and fears. You can talk of things as they occur to you. They do not have to be in chronological order. I will record our conversation but you are free to stop the tape-recorder at any time if you wish to do so.

Names and family structure will be altered in order to preserve anonymity.

The intent of this study is to provide insight into the lives of hearing impaired children within the context of the family. It is my hope that focussing on the experiences of fathers may increase our understanding of the needs of both fathers and the whole family. Thankyou for your time and cooperation.

Margaret Kay

Appendix D

PERSONAL STATEMENT

For Wertz (1984, p.42), it is most important that phenomenological research begin "with a bracketing suspending of preconceptions and a fresh immersement in the lived reality to which the description refers". Following the foundations laid down by Husserl, bracketing allows for the awareness of any preconceptions so that researchers "do not impose them on their research participants" (Becker, 1986). "Objectivity...requires me to recognize and affirm both my experience and the experience of others...experience is there, for all of us, and it cannot be objectively eliminated" (Colaizzi, 1978, p.52).

My personal experience gives me an insight into the phenomenon being researched from the perspective of being a mother of a hearing impaired child and a teacher of the hearing impaired. I have also been a teacher of children with normal hearing and have two other children with normal hearing. Being both a parent and a professional working with the hearing impaired and their families means that I have "sat on both sides of the table" and have felt both secure and uncomfortable at different times in different "seats". Part of my motivation to do this research project is that I would like to see the "table" removed in order for professionals and parents to work together in the best interests of the hearing impaired child and the family.

During the interview which I conducted as a pilot project for this research I found myself at first not only agreeing with the resentments that the parents had developed against various doctors and educators with whom they have had contact, but also adding my own negative experiences and feelings to the conversation. Some positive interactions were also remembered but it was the negative ones upon which we focussed. As I looked back on that interview I wished that I had directed more time towards the relating of the experiences which have had a positive effect on the child and the family. In the subsequent interviews used for this study I attempted to use open ended questions about positive experiences, or the relating of an event which had helped my family, in an attempt to allow for a broader perspective. We can learn as much from the good as from the bad.

One of the problems faced by professionals and parents alike is that there are so many different factors which can affect hearing impaired children and their families. Such factors are outlined briefly in Chapter 2 of this study. In order to illustrate my perspective and in an attempt to shed any preconceived bias I will look at one of the areas where families of a newly diagnosed hearing impaired child have to make decisions. This is the area of mode of communication. (It is not an area where decisions have to be made by deaf parents with a deaf child because the language of the home, sign language, is already established for the deaf child to learn in the same natural way that hearing children learn from their hearing parents).

The method of communication used to teach the child, both at home and at school, has far-reaching effects on the life of a hearing impaired child, and upon the family. My son uses oral speech in order to communicate and has only a slight knowledge of sign language. There is continual controversy about the merits of manual communication versus oral communication.

The field of manual communication is further confused by the use of different sign languages. The two most commonly found in North America are American Sign Language (ASL) and Signed English. ASL is recognized as a distinct language with its own content, form, and use. It is the language used by the deaf community. Signed English is an example of a manual representation of spoken English which is often preferred by elementary schools, and generally only seen there, especially in those with an oral component to the program. It is also preferred by parents where English is the language of the home. Sign and speech are often used simultaneously, especially with children who have some residual hearing. This is called Total Communication. It sounds as if it should be the perfect answer, a compromise, but that is not the case. As with most compromises there are several problems surrounding its use. Firstly, it is slow. It is difficult to sign as fast as we speak when including every small word and morphological marker. Secondly, it is hard to include every sign in a perfect word-for-word combination. Thirdly, it is difficult for a child to attend to two visual signals (speech reading and sign) as well as the auditory signal. Positive factors are that the language, english, is already known by the hearing parents and the hearing teachers. It can be used as a support or assist to help the learning child communicate and make sense of an unclear auditory signal. Advocates for the use of ASL want that language to be used exclusively in both social and educational settings. This is understandable because it is a distinct language and the lingua-franca of the deaf community. However, for hearing impaired children from a hearing family it is not the language of the home, which is where communication begins.

All these facts I have assimilated gradually over a period of years. When my son was small I did not know that I had any choices or that the communication method used by our family would have such far-reaching effects on his life. When he was diagnosed as having a bilateral, severe to profound, sensorineural hearing loss we were living in Canberra, Australia. The philosophy of the teachers and program for the hearing impaired in that place, at that time, followed the oral school. I was immersed in teaching him to listen, to use his residual hearing, and to speak. He now uses oral speech as his method of communication and has managed, after some very rough starts, to do well in a regular educational setting. However, his speech and his behaviours are somewhat different from ours. He often mis-hears or fails to hear what people say, making his life full of confusions and frustrations. He falls between two worlds and does not have strong ties to either the hearing or the deaf community. During the school term he lived with a family with one hearing and one deaf parent. Academically he has achieved success but at the sacrifice of social development and emotional stability. Looking back it is hard to say whether I would have done things differently. Knowing what I know now would I have pushed him harder to become a part of the deaf culture? The answers are not clear, even after more than twenty years. He can still make those decisions for himself but he will do so without the support of a childhood surrounded by friends with like-experiences. It will be like starting another life, separate from his family.

I do not feel regret either for myself or for him, because I know there are no easy answers, rather I feel concern for the way in which information about hearing impairment is disseminated and compartmentalized leaving families confused and resentful. This happens in two ways. Firstly, there are several disciplines involved: education, audiology, numerous medical specialists, and possibly social workers or family counselors. Secondly, too often any one discipline may feel so strongly about one factor that they fail to see the child within the whole family environment.

The two things of which I am becoming increasingly aware are that hearing impaired children need to learn language and they need to develop good peer relationships. They should be supported as they do this within the framework of their family. The goal should be the same as for any other child: we want them to develop socially, emotionally and academically to the best of their ability. The method of communication that they use should be the one with which they will best learn language and which will allow them to develop socially and emotionally within their family and environment.

I do not advocate any particular methodology or adhere to a specific ideology. Needs will vary between families and among children. Perhaps the best way to help and support the hearing impaired child and the family is to be alert to these differences.

A specific reason for choosing my research topic is the importance that I place on families. Within the family unit much attention has been placed on the mother-child relationship (Gallagher, Cross, & Scharfman, 1981) and less attention paid to the role of the father and the effect that having a hearing impaired child has on that parent. Within my own family my husband was certainly the member who received the least attention and consideration. This was especially true when our hearing impaired son was young.

Hearing impaired children begin life within the family and it is the family which has to make decisions for the development of those children. Educators have long recognized early intervention, working with the family, as a major tool for the advancement of the hearing impaired child's social, emotional, developmental, and academic skills (Goppold, 1988; Mendelsohn, 1981). High levels of parental stress are frequently associated with the family of a hearing impaired child (Gallagher, Beckman, & Cross, 1983; Moores, 1982;

Mendelsohn, 1981; Luterman, 79) and my own family is no exception to this finding.

I abandoned my career as a teacher when our hearing impaired son was born and chose to stay home and care for him. I was the parent who was free to take him for medical appointments, who learned from the itinerant teacher who came to our house how to stimulate speech and language development, and who had daily play/learning sessions with our son. Because of my training and experience it seemed a natural role. I was the one who stayed up at night (I didn't have to go to work the next day), the one who read the books, sent away for literature and programs. I chose to do all these things. In a short space of time I unwittingly set myself up as the one who "knew what to do"! When my husband asked me questions about hearing impairment I was so exhausted with the total involvement demanded of me that I didn't want to talk about hearing impairment in any depth, I even resented that he should be asking me. If I had learned what was needed why hadn't he? At that time he felt it was more important to be at work than at a medical appointment and I agreed with him. Looking back I think that a contributing factor to our problems was that the medical and educational personnel did not expect him to attend meetings either. When, out of concern, he questioned what was happening for our son, I took it as critisism. If he made a suggestion which would help me, I rejected it. I knew better! In this way our family became divided, not just because of our son's problems but because we were unable to work together, to listen to or understand each other.

Since that time our family has lived apart and come together again. We have learned to listen to each other and we try very hard to understand the needs of other family members. Our family is important to us but within that framework we attempt to allow for individual needs. We have learned from our own past experience and we are fortunate to be able to use that knowledge to strengthen our family today.

It is my hope that listening to the experiences of other parents of hearing impaired children, looking at their experience from the father's perspective, and analysing those experiences in order to illuminate meaning, may help to extend our understanding of such families. Ultimately this information may be combined with other insights to influence the way in which families with a hearing impaired child are supported by professionals who work with them. It may also enable individual family members to support each other more fully through similar experiences.