

“My Child has a Cochlear Implant”: Exploring
Mothers’ Stories Using Narrative Inquiry

by

Shelley Berezon
BSN, University of Victoria, 2002

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ABSTRACT

Parents of a child who undergoes cochlear implantation typically go through an incredibly difficult and lengthy process. Mothers tend to carry the brunt of this stress because they are the most likely parent to be the main caregiver of children, particularly children who have special needs. Many aspects of cochlear implantation have been researched; however little is known about the experiences of the primary caregivers of children who make use of this technology. Using Narrative Inquiry this study explores the experiences of mothers whose children have undergone the cochlear implantation process as told through their stories. A thematic analysis revealed three interrelated themes: (a) struggling with new realities, (b) feelings of uncertainty and isolation, and (c) moving on. The findings suggest that the mothers experienced a personal transformation: they found new ways of thinking and being. Implications for practice focus on supporting mothers' health and well-being so that they may ultimately provide for and support their children's needs. Specific recommendations for practice have been made.

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DEDICATION

To my son Ryan

who has taught me so much about the world and myself.

Eyes to Hear

To have a voice with no voice

Meaning is in your hands

Intuition becomes a language

To convey ideas of the mind, in silence

It takes touch to be seen, eyes to be known

Pure joy of not knowing is innocence

My tender heart how can I help you

It is agony seeing beyond what will be

Inevitable pain, mixing tears yours and mine

To live the life of normality was assumed by me

Unquestioned by you

Vulnerability is now so apparent

How can we know without eyes to hear

You see for me

I hear for you

Together our world is more

CHAPTER ONE: INTRODUCTION

Becoming a mother is an enormous life event; many women experience a plethora of emotions. Discovering that your child has a severe to profound hearing loss or is deaf can be devastating. Fortunately, we live in a time when advanced medical technology is available to help some of the children who experience this level of hearing loss. This technology is referred to as *cochlear implantation* ([CI] see Appendix A for an explanation of how it works). An implant does not cure deafness; however, it does provide greater opportunities to improve a child's communication skills (Luterman, 2003). The parents of a child who undergoes CI experience an incredibly difficult and lengthy process that typically involves deciding whether their deaf child will benefit from a CI to helping their child learn to hear and speak with the aid of an implant.

Research Aim

Mothers are the most likely parent to be the main caregiver of children, particularly those who have special needs. The lengthy, complex CI process is typically a difficult and stressful time for parents, and mothers tend to carry the brunt of this stress. Even though a large amount of research has been conducted on CIs from a variety of viewpoints, there is still a gap in the literature. Little is known about the experiences of the caregiver of a child who undergoes a CI. I believe that this is significant because it is often the mother who cares for, supports, and advocates for the child throughout the entire experience. Thus, mothers are crucial to the success of their children's use of CIs, which ultimately make it possible for their children to be connected to a hearing world. I have focused my research on the stories that mothers tell of their experiences when their

children went through the CI process. Following the notion that experience is conveyed in story form, a narrative inquiry (NI) approach was used as a way to understand mothers' experiences.

My main research question was, What are the experiences of mothers whose children have undergone the CI process? Other questions emerged as I contemplated what I wanted to learn: What do their stories reveal of their experiences? How do these experiences affect their health and well-being? How do society's standards of what is normal influence them? How has the social narrative of mothering shaped their mothering experience?

A Narrative Inquiry Approach

The intent of this research was to understand the experiences of mothers whose children have undergone the CI process, and NI fits well with this exploration. Narrative, experience, and story are central concepts to this approach; other influencing factors include person, culture, history, and time (Clandinin & Connelly, 2000). NI entails the reconstruction of a person's experience in relation to others, to a social milieu, within a context of time (Clandinin & Connelly, 2000; Frid, Ohlen, & Bergbom, 2000).

Theoretical Perspectives

For the theoretical framework underlying this NI study, I drew upon social constructivist knowledge and principles as well as feminist and developmental perspectives. Assumptions within the social constructivist paradigm include (a) multiple realities exist that have been socially constructed and influenced by history and culture, (b) meaning is often co-constructed, (c) the values of the researcher are assumed to exist, and (d) subjectivity is an integral part of the research (Avramidis & Smith, 1999; Morrow, 2007). NI fits well with these beliefs because it entails the reconstruction or

recreation of a person's experience, while at the same time recognizing influencing factors such as person, culture, history, and time (Clandinin & Connelly, 2000).

Central Assumptions

My main assumption about mothers of children who have received a cochlear implant is that these mothers have experienced an emotionally challenging and disruptive event in their lives. They have undergone a long, demanding, and potentially stressful CI process and are in the midst of experiencing life with a child who has a cochlear implant.

Below are other noteworthy assumptions:

1. Knowledge is socially constructed: It is local, partial, and co-constructed (Denzin & Lincoln, 2005).
2. Meaning making is individual, and because we are relational beings, meaning making is also co-constructed (Clandinin & Connelly, 2000; Riessman, 1993).
3. Experiences are unique and shared.
4. We can be known to others through/by the stories we tell (Lieblich, Tuval-Mashiach, & Zilber 1998; McLeod, 1997).
5. There is a dominant ideology that has the greatest influence on our culture's overall outlook; we live in a highly patriarchal society.
6. Men and women have been socialized and constructed into gender roles by the environment, culture, and their experiences. Traditional gender roles prevail whereby women perform the majority of the domestic work, as well as most of the childcare and caregiving. Specifically, mothers are most responsible for children's health and well-being.
7. People's health and well-being are influenced by their experiences.

8. Western cultures maintain the prevailing view that people with disabilities are less valuable than are 'normal' people and are typically a burden to society.

Summary

Many children who have a profound hearing loss have an opportunity to experience sound through CI, and mothers are generally essential to the success of their children's use of this technology. I have used a NI approach to gain an understanding of mother's experiences of having a child who has gone through the cochlear implantation process. Understanding what mothers' experience during their child's cochlear implantation process can build knowledge about this phenomenon and can inform health professionals who work with these families.

CHAPTER TWO: LITERATURE REVIEW

In this section I explore three areas of the literature related to experiences of mothers whose children have undergone the CI process: becoming a mother, discovering that a child is deaf, and the process of CI.

Mothers of children who have received a cochlear implant have experienced many transitional events in their lives, one of which is becoming a new mother, and research has shown that women experience enormous change with new motherhood (Harvey-Vallender, 2005; Mercer, 2004; Rogan, Schmied, Barclay, Everitt, & Wyllie, 1997). The society in which she lives greatly influences how a woman sees herself as a mother. I believe that it is important to consider societal factors in discussing the role of motherhood because they potentially influence woman's experiences.

Another significant event that a mother sometimes experiences is learning that her child is deaf. Past studies have shown that this can be a very difficult time that requires yet another shift in her reality and the need to deal with a plethora of new emotions (Burger, Spahn, Richter, Eisselle, Lohle, & Bengel, 2005; Seabrook & Rodda, 1991).

The third area of this review includes information about the different steps of getting a cochlear implant. The cochlear implantation process has been described as a long, demanding and potentially stressful event (Most & Zaidman-Zait, 2001). To help one understand some of the experiences mothers have gone through it is important to provide background to the process.

The final section in this chapter includes an overview of paediatric CI research from a variety of perspectives. I will initially discuss studies that have focused on the

family, followed by a brief look at research on speech and language development, educational issues, psychosocial adjustment of the children, social functioning of children, medical perspectives, complications related to CI, and technical changes.

Woman: Becoming Mother

Becoming a mother involves an enormous transformation and evolution of a woman's persona (Mercer, 2004). It can be seen as a difficult, multifactoral process that, as with any major developmental transition, requires restructuring goals, behaviours, and responsibilities to achieve a new conception of self (Harvey-Vallender, 2005; Mercer, 2004). A new mother commonly finds that she has changed in ways that she had never imagined; she has moved from a known current reality to an unknown new reality (Mercer, 2004). New mothers go through profound change and with it may experience a sense of loss, isolation, and fatigue (Rogan et al., 1997).

Barclay, Everitt, Rogan, Schmied, and Wyllie (1997) separated the process of becoming a mother into six categories: (a) realization: facing the overwhelming process of becoming a mother and the consequences on her life; (b) unreadiness: feeling unready for the reality of motherhood; (c) drained: a sense of having given everything and of being emptied out that results from the physical, mental, and emotional demands associated with this new role; (d) alone: a feeling that many mothers described that is typically associated with feeling unsupported; (e) loss: an experience that occurs in a variety of areas and in a variety of ways: loss of time, of control over one's life, of sense of self; and (f) working it out: the development of skills and increasing confidence in being a mother and caring for her baby.

Dominant ideologies (see Appendix B for definitions of terms) ultimately influence how we see ourselves. In considering what it means to be a mother, we take

cues from the people around us, from our culture, and from society. Social norms define proper and improper behaviours and thus create a prescribed maternal role (Oakley, 1979; Rogan et al., 1997). The normalization of motherhood is heavily influenced by medical discourse as well as personal, historical, social, and institutional practices (Aston, 2002). Hartrick (1996) contends “the Western perspective of what a healthy, mature self [is], one that is differentiated and independent, is in direct opposition to the Western perspective of a good mother” (p. 317). According to Oakley, a major expectation of a good mother in Western society is abnegation of self. It is therefore normal and expected that women will self-sacrifice for their children. This notion has been described as the institution of motherhood, the way that women become mothers in industrialized society today (Hartrick, 1996; Mercer, 2004; Oakley, 1979).

How the concept of *normal* is created and perceived can be carried over into all aspects of life; for example, a normal marriage, a normal job, and a normal child. What happens when something is not normal? In our society this process of normalization leads to a notion of deviance. What is not normal, or those who do not subscribe to and practice normal social forms, may be considered abnormal or deviant (Aston, 2002).

Mothering Other-Than-Normal Children

Every day babies are born who are not healthy or do not meet the criteria for what our society typically defines as normal. When this occurs a quiet, personal tragedy can transpire for the mother (Bruce & Schultz, 2002). How does a mother negotiate this new role of being a mother of a child with a disability? In our society we have only prescribed roles of *other* or *not normal*; these in turn become *disabled*.

A mother’s knowledge that her child has a disability may be evident at birth or may not be experienced until later. Nelson’s (2002) metasynthesis of studies that have

addressed mothering other-than-normal children identified common emotional themes inherent in the accounts of mothers during this initial discovery phase: injustice, fear, anxiety, grief, shock, disappointment, despair, and guilt. When the discovery of the disability occurs later, mothers have to cope with not only the shock, confusion, and anxiety related to the diagnosis, but also the loss of the child they had previously known. It is often a loss of their dream of how their child's and their own lives would have turned out (Nelson, 2002).

Regardless of whether a mother learns about her child's disability at the time of the birth or later, the reaction, most commonly known as *grief*, is often like that when someone close to her dies (Oekerman, 2001). Grief is a natural human response to a significant loss (Blaska, 1998). It is enduring and usually precipitated by a negative life event or episode that retains a physical presence, a psychological presence, or both (Blaska, 1998; Bruce & Schultz, 2002; Oekerman, 2001).

The emotions typically experienced in grieving are not necessarily felt in any particular order; they can be felt simultaneously and are frequently reexperienced. Grief often expands throughout the lifespan into what has been called chronic grief, chronic sorrow, or nonfinite loss (Blaska, 1998; Bruce & Schultz, 2002; Reisz, 2004). Blaska maintained that it is important to recognize that there are times when these intense feelings disappear for short and sometimes long periods of time. It is the recurrence of emotions that Blaska called *cyclical grieving*. Specific events, times of transition, or a new developmental stage in the child's life often trigger the reexperience of grief. The reaction and experience are unique for each individual.

Raising a child with a disability often results in profound emotional experiences for a mother and can affect her health and general well-being (Gray, 2003; Helitzer,

Cunningham-Sabo, VanLeit, & Crowe, 2002). Mothers are the parents most likely to stay at home to care for the child, and as a result, they experience significantly greater stress related to activities of daily routines (Helitzer et al., 2002; Pelchat, Lefebvre, & Perreault, 2003). In general, mothers experience greater emotional distress, parenting stress, social isolation, and career disruption; they also take on the primary role in the medical referral process and deal with their child's educational problems (Gray, 2003; O'Brien, 2004).

It is important to keep in mind that a number of mothers find great joy in raising a child with a disability in spite of the strain, stigma, and social suffering that can be associated with it (McKeeve & Miller, 2004). Many mothers have described how their children have greatly enriched their lives and expressed intense feelings of love, pride, and respect (McKeeve & Miller, 2004; Nelson, 2002).

Deafness is a significant unexpected reality for hearing parents that has been linked with great psychosocial stress for parents and other family members (Burger et al., 2005; Seabrook & Rodda, 1991). It is a challenge to raise any child to responsible adulthood, however, when a child has a special need, the task of parenting may seem overwhelming (Luterman, 2003). According to Seabrook and Rodda's study on parental response to deafness, parents eventually transition to the acceptance stage, which typically includes constructive action such as restructuring their lifestyle and reexamining their value systems. They maintained that parents eventually emerge from the grieving process with renewed dreams, goals, and expectations of their child, but added that these parents will continually reevaluate their values and attitudes toward their child's hearing loss.

Parents typically look for all options available to help enrich or improve their child's life, and CI is a viable option for many children who have a profound hearing

loss. It is important to note that an implant does not cure deafness; rather, it provides greater opportunities to improve a child's communication skills (Luterman, 2003).

Cochlear Implantation Process

Paediatric CI involves a series of multifaceted stages. First, the parents must decide whether an implant is what they want for their child. Second, the CI program must accept the child as a candidate. Third, once the child has been accepted, the parents must then prepare him or her for the surgery and the changes that are about to occur. Fourth, the surgery itself takes approximately three hours and requires a typically short recovery period. The final and longest stage is rehabilitation, during which the child learns how to hear using the CI; this period can last for many years. Each of these stages is complex in and of itself and can potentially have its own issues and difficulties.

Parental Decision

Deciding whether their child will receive a CI is characteristically very difficult for parents (Most & Zaidman-Zait, 2001; Zaidman-Zait, 2007). Many parents agonize over the decision and describe the process as the most difficult in their lives (Luterman, 2003). The choice to implant is a life-altering decision that parents must make typically without consulting their child and without any assurance that the child will appreciate the decision to implant when she or he is older (Luterman, 2003). Conversely, Sach and Whyne (2005) showed that the majority of parents found the implantation decision relatively straightforward because "they believed their child had nothing to lose and everything to gain" (p. 402).

When parents are in the process of making a decision, they typically begin to gather information by contacting other parents whose child already has a CI and teachers who have experience in working with children with CIs (Allegretti, 2003). CI is an

irreversible, invasive procedure that requires an enormous commitment on the part of the family in both personal and financial terms (Most & Zaidman-Zait, 2001; Russell & Coffin, 1999). Parents must weigh the pros (benefits) with the cons (potential complications) as well as consider the ethical issues surrounding this decision. For an overview of the potential benefits and complications of CI, see Appendix C.

Parents of children who are prelingually deafened—that is, deafened before the child has learned oral language, usually by the age of two years—face the added pressure of time in an already difficult decision. The human brain is set up to develop the auditory system by the age of five years; after this point neural plasticity abates, and with it the ability to learn oral language (Callanan & O’Connor, 1996; Hehar, Nikolopoulos, Gibbin, & O’Donoghue, 2002). For this reason it has been determined that, for prelingually deafened children to receive the greatest possible benefit from a cochlear implant, the earlier it is implanted, the better (Edwards, 2003; Hehar et al., 2002). For those parents whose child has lost his or her hearing due to meningitis, timeliness is particularly important. There is only a brief window of opportunity for this intervention before ossification of the cochlea occurs, which may be as early as two months after the illness, making it nearly impossible to position the device in the right location (Hehar et al., 2002; Pedersen, Jochumsen, Madsen, Koefoed-Nielsen, & Johansen, 2000).

A vast amount of literature has reported personal and social difficulties and problems for deaf children, including in areas such as self-esteem, social-emotional adjustment, and family stress. An implant will not solve all social-interaction problems; however, there is evidence of significant decreases in loneliness, social anxiety, and distress, as well as generally improved well-being (Nicholas & Geers, 2003). Interestingly, Allegretti’s (2003) research found that parents typically based their

decision on CI on their desire to improve their child's communication capability rather than social skills or social contact.

There is a very real pressure from the Deaf community on people who have significant hearing loss to retain their deaf status and avoid the lure of joining a more normative society (Allegretti, 2003). Many people from the Deaf community possess what is known as Deaf pride: They see deafness as a way of life rather than a disability and believe that children should not receive implants (Allegretti, 2003). As a result, the decision-making process can be further complicated for families who are familiar with the Deaf community and wish to consider all options from a variety of perspectives.

As part of the decision-making process, parents must also make choices regarding their child's educational placement and mode of communication (Most & Zaidman-Zait, 2001). Most CI programs will require that children have a primary re-habilitationist and be enrolled in an educational re-habilitation program with an emphasis on auditory/oral development before they will accept them as candidates. This poses particular problems for families with children under the age of five because there is often little or no government assisted funding for education for this age group, and the parents may be left with the responsibility for securing funding for their child's re-habilitation.

Once the parents have decided that they want their child to receive a CI, the child must undergo an evaluation and approval process. At this stage many parents become anxious about whether or not their child will be eligible to receive an implant (Allegretti, 2003). Intense evaluation assists the team in the decision-making process with regard to candidacy.

The Team: Pre-implant Assessment

Paediatric CI is a multifaceted therapeutic treatment that requires the services of a multidisciplinary team, with contributions from surgeons, nurses, audiologists, speech-language pathologists, psychologists, special educators, and parents (Most & Zaidman-Zait, 2001; Russell & Coffin, 1999). The decision to offer a child a CI is very complex and requires that a number of professionals consider many issues related to the child and family (Edwards, 2003).

Selection of appropriate candidates is an ongoing topic of debate. Candidacy and selection issues are continuously being explored, and studies have often been aimed at determining whether the techniques for selection are appropriate (Edwards, 2003). Over time, selection criteria have gradually broadened as a result of the increasing experience of cochlear implant teams, improvements in technology, and evidence of successful outcomes in a wider range of children (Edwards, 2003; Luterman, 2003). Some of the factors that appear to affect success include the status of the cochlea, the child's auditory memory of speech and sound, the educational program, and the family's motivation and commitment (Russell & Coffin, 1999). Every cochlear implant program has its own specific list of criteria; Appendix D outlines the criteria for BC Children's Hospital's paediatric cochlear implant program.

A crucial medical criterion is that the cochlea is open and able to accommodate the insertion of the electrode (Pedersen et al., 2000), which is determined by using a computerized axial tomography scan (Russell & Coffin, 1999). Other tests and/or evaluations that the CI team carries out may include an otologic history, physical exam, audiologic evaluation, auditory brain stem response evaluation, speech and language

evaluation, and psychological evaluation of the child and parents (Luterman, 2003; Russell & Coffin, 1999).

The parents' role is vital to the success of a CI (Nikolopoulos, Lloyd, Archbold, & O'Donoghue, 2001; Russell & Coffin, 1999), and parents are therefore also evaluated during this phase of the CI process. They must agree to take on specific responsibilities that are imperative for the child to succeed in using the implant, make choices that ensure that their child receives the necessary support to optimize the use of the implant, attend numerous appointments and learn to check and maintain the equipment, and, most important, nurture their child's language and overall development (Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos, 2002; Nikolopoulos et al., 2001).

Parental expectations related to the success of CI have been considered so important that decisions on postponement, rejection, and selection of children for implantations have been based on these expectations (Nikolopoulos et al., 2001). Nikolopoulos et al. and Russell and Coffin (1999) suggested that one of the major influencing factors that potentially affects the success of CI is the commitment of the family.

Luterman (2003) maintained that parental disappointment can limit the effectiveness of the re-habilitation and must be addressed early. Some have contended that pre-implant counselling is essential to ensure that the parents' expectations are realistic and thus will ensure positive outcomes (Nikolopoulos et al., 2001). This involves giving parents information on the limitations of the intervention, on the need for their involvement in the child's rehabilitation, and on the cost of rehabilitation. Conversely, the results from Edward's (2003) study suggest that unrealistic parental expectations are not altered by pre-implant counselling and are not related to the outcome.

Preparing for the Surgery

Parents deal with considerable anxiety and fear prior to the surgery (Most & Zaidman-Zait, 2001; Zaidman-Zait, 2007). Team members work with the parents to ensure that the child is prepared for the CI operation, which can be particularly difficult depending on the child's age and communication skills (Russell & Coffin, 1999). The child needs to learn new concepts such as hospital, operation, and CI through whatever means of communication is required. For example, a stuffed animal with a toy external CI device can be used as a visual aid and for hands-on play/learning. Photographs and books also work well to help parents familiarize their child with these new concepts.

The Surgery and Postoperative Period

The surgery is a stressful time for both the child and the parents (Allegretti, 2003; Zaidman-Zait, 2007). Because most children who receive CIs are young, the parents are usually present during the anaesthesia induction to facilitate communication and reassure their children (Russell & Coffin, 1999). Parents are typically anxious throughout the surgery about complications during the surgery, postoperative infection, and/or pain. They enter the recovery area more quickly than would otherwise be typical because most staff are unable to communicate with the deaf (Russell & Coffin, 1999). Discharge from the hospital generally occurs the day after surgery. During the first week postoperatively there is usually very little pain; however, some children may experience slight vertigo.

The initial activation and programming of the device usually occur at about six to eight weeks postoperatively. Typically, much support is needed for the child and the parents during this time because of the increased stress and anxiety (Allegretti, 2003; Zaidman-Zait & Most, 2005). Hearing sounds for the first time may be frightening for the child, it is therefore important to provide sound stimulation that is audible yet

comfortable for the child (Allegretti, 2003; Russell & Coffin, 1999). Subsequent programming sessions, typically called *mapping*, are held to adjust the numerous electrode parameters as the child becomes used to using the device. These sessions may occur frequently depending on the needs of the child and his or her ability to cope with the changes. If the family lives far from the CI centre, this could increase the stress on the parents as a result of time and financial concerns.

Re-habilitation

Rehabilitation is the process of helping a person to relearn old skills that were somehow lost, whereas habilitation is the process of helping a person to develop or learn new skills or abilities (Laughton, 1997). Children who are deaf may or may not have had former hearing and speech skills imprinted in their memory. Therefore, we cannot be certain whether they are relearning old skills or developing new ones. I suggest that it could potentially be both; as a result, I have chosen to refer to this stage of the CI process as *re-habilitation*.

This stage in the CI process is the most challenging yet the most rewarding (Russell & Coffin, 1999). Parental involvement in this phase of the process is intense and significant (Most & Zaidman-Zait, 2001). Ongoing speech and language therapy occurs three to five times a week with a professional who is specifically trained to work with children with cochlear implants (Russell & Coffin, 1999). However, much of the child's oral language work is done with his or her parents.

Children with prelingual profound deafness are the most difficult to re-habilitate because they have little, if any, previous experience of sound (Callanan & O'Connor, 1996). The acquisition of intelligible speech is normally accomplished only after lengthy re-habilitation (Most & Zaidman-Zait, 2001). Re-habilitation is most often based on a

family-centered intervention process in which the professionals and the parents build a collaborative relationship. It is important to note that parents should be considered clients as well as partners because of the potentially stressful impact of the process on the parents' own needs and interests in dealing with this stress (Most & Zaidman-Zait, 2001).

Research on Paediatric Cochlear Implantation

As previously discussed, paediatric CI is a complex therapeutic treatment that requires the services of a multidisciplinary team that includes surgeons, nurses, audiologists, speech-language pathologists, psychologists, special educators, and parents (Most & Zaidman-Zait, 2001; Russell & Coffin, 1999). There is, therefore, a substantial amount of literature on this subject that involves a variety of approaches from a diversity of perspectives. In this section I discuss paediatric CI research that focus on the family, followed by a brief overview on research focusing on (a) speech and language development, (b) educational issues, (c) psychosocial adjustment of the children, (d) social functioning of children, (e) medical perspectives, (f) complications related to CI, and (g) technical changes.

Parental perspectives are critical in many paediatric CI research studies whether they are the focus of the research or the parents are utilized as resources for information. Parents typically spend the most time with these young children. Consequently, their input is important to obtain data to assess the outcome of the CI (Archbold et al., 2002; Nikolopoulos et al., 2001). Many of the studies mentioned in the previous section of the literature review focused on parental input for their data.

Research in the area of parental experience to date has focused on limited evaluations of parents' anxieties, responses, perceptions, expectations, and adjustment related to their children's CI (Zaidman-Zait & Most, 2005). Even though the role of the

parents has been determined as vital to the success of the implant and their perspectives are critical to many paediatric CI research studies, there has been very little mention of the parents' experience with a child who undergoes the implant process (Archbold et al., 2002; Nikolopoulos et al., 2001).

Zaidman-Zait's (2007) most recent study utilized a critical-incident technique as a framework to assess the coping experiences in parenting a child with a cochlear implant. The aim was to develop a comprehensive categorical system that would represent the resources that parents identified as affecting their coping experience. Zaidman-Zait distinguished 20 categories based on parents' descriptions, explanations, and attributions of meaning to their experiences. Their study results indicate that "the coping experience of parenting a child with a CI was determined by various sources of influence associated with social contextual aspects, with the parent himself or herself, and with the child" (p. 234). Zaidman-Zait identified the need for further studies in associated areas, such as what hinders parental coping processes and the differences between mothers' and fathers' coping processes.

Calien and Hugo's (2002) study on the coping mechanisms of parents whose children have CIs did not have much to do with determining whether the parents were coping. They examined the parents' knowledge of and attitude toward cochlear implants, the implant program, and the communication development of the child who received the CI. Using a self-administered questionnaire, the researchers reported that most parents had sufficient knowledge and appropriate attitudes and were generally satisfied with the services, but they also identified areas for improvement and confirmed the need for further investigation of parents as influential variables.

By means of a survey, Most and Zaidman-Zait (2001) sought information from parents to develop an intervention program based on their needs. The data show that the parents considered a vast number of topics highly important, which suggests that parents need extremely diverse information on the CI process. In 2005 Zaidman-Zait and Most turned their focus to mothers and maintained that mothers participate more actively in their children's intervention program than do fathers. The focus of the study was on conducting a comprehensive evaluation of parental expectations following CI and examining parents' perceptions of a number of variables. Using three questionnaires, Zaidman-Zait and Most found that mothers have high expectations for their child's communication, social, and academic abilities following CI.

Similarly, Nikolopoulos et al. (2001) analyzed parents' views to determine whether the results of the intervention met the parents' expectations. Using a questionnaire, they set out to assess pre-implant expectations and observe changes and concerns at one, two, and three years following implantation. Their findings demonstrate the ability of CIs to meet or surpass parents' expectations.

Sach and Whynes (2005) conducted one of the few qualitative studies on the topic of parents' perceptions of paediatric CI over time. Using semistructured interviews, they found that time plays an important role in family experiences of CI and that expectations are continually revised throughout the process. Parents share the hope that the implant will enable their child to function in a hearing world. The main difference between family perspectives was in educational preferences, and the comments were most often related to the lack of resources within the system.

Another distinctive qualitative study is Allegretti's (2003) case study that involved a single family with a child who underwent CI. The family was interviewed

before, during, and after implantation to evaluate the effects of a CI on the child and her family. Allegretti's findings reveal that the family progressed through several phases of adaptive responses before and after the CI procedure that reflected common themes of ambivalence, excitement, fear, anxiety, impatience, and transformation.

Review of Other Literature Related to Cochlear Implantation

Although many prelingually deafened children typically acquire language after receiving a CI, the outcomes and benefits vary enormously (Houston, Ying, Pisoni, & Iler Kirk, n.d.). Multiple factors can potentially affect the outcome, some of which are age at the onset of deafness, the duration of deafness, the age of implantation, the speech processor type, the number of implanted electrodes, the communication mode, the duration of the implant use, and the linguistic environment (Iler Kirk, Miyamoto, Ying, Perdew, & Zuganelis, 2002; Stallings, Iler Kirk, Chin, & Gao, 2002).

The CI outcome is typically measured in terms of the child's perception and production of speech (Edwards, 2003; Hehar et al., 2002; Russell & Coffin, 1999). The speech and language development of a child who has received a CI is another major focus of research studies. Examples of these investigations include pre-word-learning skills (Houston et al., n.d.), parent word familiarity and language development (Stallings et al., 2002), and conversation fluency (Tye-Murray, 2003).

In 2002 Preisler, Tvingsted, and Ahlstrom conducted a longitudinal psychosocial study of deaf children with CIs to gain a broader perspective on the development of language and communication by exploring patterns of communication between children with CIs and their parents, teachers, and peers in natural interactions. These same participants participated in another study that Preisler, Tvingsted, and Ahlstrom (2005) conducted that focused on exploring the experiences of children with CIs. This study

explored (a) the children's memories of the implant operation and the time after, (b) hearing capacity with the implant, (c) speech perception, (d) speech production, (e) the use of sign language, and (f) peer relations.

CI research with an educational focus has produced a variety of outcomes. Daya, Ashley, Gysin, and Papsin (2000) evaluated the effect and relationship of paediatric CI on educational placement and speech-perception ability. Geers (2003) examined the impact of educational factors and determined that early CI is a cost-effective procedure that allows children to participate in a normal school environment. Chute (2003) identified educational challenges and barriers for these children.

Some researchers have evaluated the social functioning of children with implants. Bat-Chava and Martin (2002) explored sibling relationships of deaf children and compared them with sibling relationships of children with CIs; they found improvements in the relationships of children with CIs. This supports previous findings that CIs have been useful in bringing the social functioning of children who are deaf to the level of peers who use hearing aids successfully (Bat-Chava & Martin).

Nicholas and Geers (2003) set out to document the psychosocial adjustment of school-aged children who use CIs. They used questionnaires to examine parents' satisfaction with the influence of the implantation process on their child's life and on their family's life in general. They also used a self-report instrument to assess children's perceived self-competence and compared those measurements with the parents' ratings of social-emotional adjustment. They found that the children perceived high levels of perceived self-competence, and the parents rated their children's self-image and social-emotional adjustment as good.

From a medical perspective, research often explores surgical procedures and postoperative recovery issues. Improvements in surgical techniques and decreases in complications have resulted from many of these studies (Cohen, 2004). Other studies with a medical focus, such as that of Hehar et al. (2002), examined the feasibility of CI for children younger than two years with regard to the surgery and functional outcomes. They found that the earlier the child receives an implant, the better the outcome. Hehar et al. maintained that their findings have been further supported by a number of developmental studies that identified critical periods during which a developing central nervous system can use sensory information to form linguistic structure and therefore critical periods for language learning. Studies such as that of Hehar et al. have provided evidence that has resulted in changes in the candidacy requirements for paediatric CI.

As with any surgery, CI has the potential for complications, which have been thoroughly explored in a variety of research studies. According to Kubo, Matsuura, and Iwaki (2005), complications associated with CI can be classified as minor, which include tinnitus, dizziness with or without vomiting, taste disturbance, infection, and facial palsy; or major, which include facial nerve stimulation, poor response of the auditory nerve, electrode exclusion, device migration, infection, electrode misplacement, and device failure. However, research has shown a low rate of complications associated with CI surgery overall (Kubo et al., 2005).

Technical changes and improvements in the implant and speech processor have been possible as a result of research.

Summary

In the literature review I have examined three areas to provide background information for an exploration of the experiences of mothers whose children have

undergone the CI process. The information helps to provide a level of understanding of some of the experiences, such as deciding to get the implant, being accepted as a candidate, going through the surgery, then experiencing the long process of rehabilitation, and the emotional challenges that may be involved in this process.

As a woman experiences the transformation of becoming a mother, she develops a new concept of self that is influenced by societal norms as well as a prescribed maternal role (Harvey-Vallender, 2005; Mercer, 2004 Oakley, 1979; Rogan et al., 1997). While she is in the midst of negotiating this new role of motherhood, a new reality that her child is other than normal adds to the changes and emotions that are associated with motherhood. For hearing parents, raising a child who is deaf can be overwhelming, and CI offers some of these families a choice.

However, the process of CI is complex. Research has shown that parents whose children undergo CI find it a difficult and stressful time. Mothers carry the brunt of this because they are the most likely parent to care for, support, and advocate for the child throughout the CI experience.

Even though a plethora of research has been conducted on CI, there is a gap in the literature with regard to the experiences of the child's caregiver, most typically the mother (Zaidman-Zait & Most, 2005). This study focuses on the experiences of mothers whose children have undergone the CI process.

CHAPTER THREE: METHODOLOGY

I have chosen to use an NI approach for this study. My intent with this research was to learn about and understand the experiences of mothers whose children have undergone the CI process.

Narrative Inquiry

There are a variety of views about the concept of narrative and why or how it is used. One view suggests that we organize our experiences into a narrative form to make sense of and give meaning to them (McCance, McKenna, & Boore, 2001; Mishler, 1986). Others focus on the use of narrative and its social influence and function in maintaining social ties (Kvale, 1996). Many use the terms story and narrative to mean the same thing (Josselson, Lieblich, & McAdams, 2003; McCance et al., 2001; Mitchell, 1981; Riessman, 1993); others have been specific about their distinctions (Emden, 1998b; Frid et al., 2000; McLeod, 1997); and still others have purposefully avoided a definition of narrative by orienting their readers to the ways that certain terms are used and directing their exploration toward what narrative inquirers do (Clandinin & Connelly, 2000).

I have chosen to recognize narrative as both narrative as inquiry and narrative as story. Narrative as inquiry can be described as the pattern of inquiry or method, whereas narrative as story is the phenomenon or the structured quality of experience to be studied (Clandinin & Connelly, 2000). I interchange the words narrative and story but most often refer to story as that which the participants used in recreating their experiences (McCance et al., 2001).

Narratives function to create a symbolic bridge between a person's past, present, and future (Clandinin & Connelly, 2000). They also focus on the differences between past and present and future while at the same time giving the story a timeless nature (Frid et al., 2000). Placing things within the context of time is a notion to which Clandinin and Connelly referred as *temporality*: “one dimension of a metaphorical three-dimensional narrative inquiry space: the personal and the social create the second dimension and place the third” (p. 50). Clandinin and Connelly argue that during any inquiry one focuses on four directions: inward and outward (internal conditions such as feelings, reactions, moral dispositions and existential conditions such as the environment), and backward and forward (temporality—past, present, and future). To explore personal experiences, we look to people's relations with themselves and others and to their environment within the context of time.

What Is Experience?

Experience is understood as “something personally encountered, undergone, or lived through” (Merriam-Webster OnLine, 2007, definition 4) or “the act or process of directly perceiving events” (definition 5). People do not have direct access to others' experiences; they must communicate with each other to learn what others have experienced (Clandinin & Connelly, 2000; Riessman, 1993). Only the individual can truly know his or her own experience, and only he or she can give it meaning.

According to Clandinin and Connelly (2000) the closest that a researcher can come to another's experience is through his or her stories. Researchers have access to the representation of someone's experience only through talk, text, interaction, and interpretation (Riessman, 1993). For this reason it is important to remember that, because meaning arises out of a process of interaction between people, it can be ambiguous

(Riessman, 1993). NI is a way to describe and understand another's experience, a way to explore the phenomenon of experience as lived and told in stories (Clandinin & Connelly, 2000).

Story and Storytelling

Stories have been told in a multitude of ways through, for example, folktales; novels; dance; music; film; television soap operas; news reports; magazines; gossip; poetry; nursery rhymes; historical, educational, and scientific texts; other literature; and art (Arvey, 1998; McLeod, 1997). But why do we tell stories? Some have said that storytelling is a natural human impulse, whereas others have suggested that it is a universal cultural activity that binds values and goals and motivates human conduct (McCance et al., 2001; Mishler, 1986; Riessman, 1993). Ultimately, storytelling can be considered a form of social and interpersonal action in that it imitates life, presents an inner reality to the outside world, shapes and constructs the teller's personality and reality, and gives meaning to one's life (Emden, 1998a; Lieblich et al., 1998; McLeod, 1997).

One of the most immediate social functions of storytelling is to enable one person to be known by another as a result of allowing that person to explore and express their inner world (Lieblich et al., 1998; McLeod, 1997). Stories give meaning to the past events and actions of a person's life, as well as access to their identity and personality (Emden, 1998a; Lieblich et al., 1998). Lieblich et al. maintained that "story *is* one's identity. . . . A story is created, told, revised, and retold throughout life. We know or discover ourselves, and reveal ourselves to others, by the stories we tell" (p. 7).

However, people's stories are never just their own (Clandinin & Connelly, 2000). Each story is an individual version of a broader cultural narrative selected from among

the main story forms available in a culture (Emden, 1998b; McLeod, 1997). Stories not only help to construct peoples' lives and provide them with meanings and goals, but also tie individuals to the culture in which they live (Emden, 1998b). Communication through storytelling transmits values and a sense of identity of social groups from generation to generation (McLeod, 1997). Embedded within stories are instructions that guide us in dealing with the complexities of life, and stories present a way for us to express and resolve problems (Arvay; 1998; Mishler, 1986). Stories have an incredible ability to bring things together so that one can see them in a different way (Emden, 1998a).

There are occasions when one's experience, and thus story, does not fit within the typical story forms found within the dominant ideologies of a specific culture. McLeod (1997) called stories that do not fit experience and experience that does not live up to the story *cultural silencing* and contended that it often involves the unwillingness of a society or culture to hear a story because it may elicit some level of discomfort; consequently, some stories will always remain hidden, untold, or silenced. I believe that it is important to uncover and hear these particular stories, to listen to the accounts of individuals whose experiences have typically been silenced or muted, especially the accounts of women. According to DeVault (1999) the language used to tell stories can never fit perfectly with an individual's experience. For women this is particularly difficult because language itself often reflects male experiences or is the language of those with greater social power and control, and it is therefore especially important to create space for women to give their accounts (DeVault, 1999).

Narrative Inquiry Research Process

The Participants

According to Daiute and Fine (as cited in Josselson et al., 2003), the search for meaning implicitly depends on the collection of multiple perspectives. Sample sizes in qualitative studies differ depending on the purpose of the study and the specific qualitative methods used (Creswell, 1998; Sandelowski, 1995). I follow the view that it is the quality of the data obtained rather than the quantity that is important (Sandelowski, 1995). In NI, vast amounts of field texts (a term used for all types of data) are produced by virtue of deep, intensive interviews (Clandinin & Connelly, 2000; Josselson et al., 2003). I conducted four interviews, which resulted in interpretive sufficiency (Denzin & Lincoln, 2005).

Because of the specific population I wished to study, I used a purposive sampling strategy (LoBiondo-Wood & Haber, 1998). After obtaining permission from the University of Victoria Human Research Ethics Review Board, I contacted a resource centre in writing (Appendix E), with a follow-up telephone call, to explain my research project and my proposal to locate potential participants. I connected with an individual from this centre who acted as a gatekeeper, an individual who is a member of or has insider status with a specific group (Creswell, 1998). I then sent a package containing 20 letters with stamped, self-addressed envelopes to the gatekeeper, who then distributed them to mothers of children with cochlear implants across British Columbia. Mothers who were interested in participating in this study contacted me directly, which helped to protect their anonymity.

I invited mothers to join me on this exploration based on criteria that included their children's age and level of speech development prior to implantation. First, the child

was required to have been deafened prelingually; there is a window of opportunity for prelingually deafened children to effectively learn oral language (Callanan & O'Connor, 1996; Hehar et al., 2002). My interest in this particular group of children is that their lives are the most affected by receiving a cochlear implant in that they potentially experience the most dramatic change concerning communication in general (Hehar et al., 2002; Nikolopoulos, O'Donoghue, & Archbold, 1999; Edwards, 2003).

The second criterion required that the child be between one and five years of age at implantation. This criterion is associated with the first, given that a child who is prelingually deafened would be under the age of five. This is also the typical age range at which children receive an implant when they are prelingually deafened (Hehar et al., 2002; Nikolopoulos et al., as cited in Edwards, 2003).

The third inclusion criterion for the study was that the child had to have received an implant within no less than eight months of the interview. I based the rationale for this parameter on my experience and assumptions: The early months postimplantation are extremely intense and full of ambiguity, and I believe that it can potentially take up to at least eight months for the mother to deal with the initial period of adjustment postimplantation. It is an overwhelming and very busy time, and after this period of time, I believe that the mother will have had an opportunity to reflect on and make meaning of her experiences.

My final criterion was that the child not have any other significant disabilities. This last condition was based on my belief that any other significant disability could add to the intensity and complexity of the mother's experience. I believe that the inclusion of this stipulation enabled me to better focus on and explore the experiences of mothers of deaf children who had received a cochlear implant.

It was my intention to create a space where further complexities, such as those brought on by prior relationships, be kept to a minimum. Therefore I made a conscious decision to invite only those women with whom I had no prior personal relationship to join me and participate in this study.

Four mothers between the ages of 34 and 46 years participated in this study. All were Caucasian and ranged socioeconomically from mid-low to high status. All were married; however, one of the women had been separated for a time. One woman was a stay-at-home mother, and the other three had full-time jobs. However, of these three, two had decreased their weekly work hours to enable them to spend more time with their children, and the third was on leave from work due to unrelated circumstances. The children who had been implanted also ranged in age: at the time of diagnosis, 6 months to 16 months; at the time of implantation, 18 months to 2 years 1 month; and at the time of the interviews, between 4 and 7 years. The children's placement in their families varied as well: Two had no siblings, one was the second of two children (the older sibling was also hard of hearing), and one was the middle of three children (the youngest sibling was also hard of hearing). Finally, the mothers whom I interviewed came from a variety of communities within British Columbia: Two were from larger centres, one was from a smaller town, and one was from a small rural community.

The Researcher

NIs are always strongly autobiographical (Clandinin & Connelly, 2000). Because researchers live storied lives and are storytellers, it is impossible merely to attend to participants' stories and ignore their own: "When in the field narrative inquirers are never merely there as observers. . . . They too are having an experience, the experience of the inquiry that entails the experience they set out to explore; . . . they are part of the

experience itself” (Clandinin & Connelly, 2000, p. 81). The beginning of a research project is the beginning of a new story. The inquiry experience, like all experiences, is a storied one, and we need to tell our own stories (Clandinin & Connelly, 2000). One of the starting points for a narrative research study is the researcher’s own narratives of experience (Clandinin & Connelly, 1994, 2000).

Reflection Process

It is important that researchers who use NI reveal and share experiences related to the phenomenon under inquiry (Connelly & Clandinin, 2000). Following this advice, I will briefly outline my position with/in the subject. I am the mother of a child who was born with a severe hearing loss and became deaf by two years of age. My son received a cochlear implant eight years ago; he was three years old at the time of the surgery. The experience of being a mother whose child has received a cochlear implant gives me certain advantages and insights into this particular phenomenon. However, it also creates specific complexities. I have attempted to address these and other issues related to my topic by taking a reflexive approach to my research, specifically by keeping a reflexive journal.

A reflexive approach acknowledges researchers’ assumptions about the situated nature of the research, appreciation for the relativity of truth, and willingness to make values explicit and demonstrate the trustworthiness of their findings (Finlay & Gough, 2003; Hall & Stevens, 1991). Reflexivity is one of the ways in which researchers can manage issues of subjectivity (Morrow, 2005).

The reflexive journal provided a safe environment in which I could reflect on my presence in the field and explore and clarify how subjective elements such as assumptions, feelings, biases, and anticipated outcomes might have influenced me as the

research (Banister, 1999; Finlay & Gough, 2003). (See the Researcher's Journal and Reflexive Journal section below for more details on journaling.)

The Research Relationship

NI is a process of collaboration that involves mutual storytelling in which both the storyteller and the recipient of the story are involved in constructing meaning (Arvay, 1998; Connelly & Clandinin, 1990). This requires a relationship between the researcher and the participant. Thus, a central concept in this inquiry approach is the participant-researcher relationship. It permits the researcher to enter and participate in the social world in ways that allow the possibility of transformations and growth (Clandinin & Connelly, 1994).

According to Hogan and Nodding (as cited in Connelly & Clandinin, 1990), creating a collaborative research relationship takes time and space. The researcher and participant come together to create a context of conversational intimacy, a place where participants feel comfortable telling their story (Corbin & Morse, 2003). Trust is essential for this to occur; as trust builds, more of the story gradually unfolds (Corbin & Morse, 2003). I believe that my situatedness and personal experience benefited the construction of intimacy in my relationship with the participants (Clandinin & Connelly, 2000). I suggest that there was a certain level of shared experience and understanding when I entered the field as a result of having a deaf child with a cochlear implant.

When a relationship has been constructed between two people, both voices can be heard. The stories become a shared narrative construction and reconstruction through the inquiry process (Clandinin & Connelly, 2000). What ultimately emerged were new stories of mothers and researcher, stories that hold new possibilities for mothers, researcher, and those who read their stories.

Clandinin and Connelly (2000) asserted that the participant-researcher relationship is always in the midst of change and that it is important that the researcher sustain clear communication throughout the inquiry process. In following this advice, I sought (a) to ensure that I made my intentions explicit, (b) to be clear about the participants' roles, (c) to help the participants to negotiate their level of involvement to reflect how much they wanted to participate rather than how much I wanted them to do so, and (d) to be sure to make explicit any potential changes in those roles during the inquiry process.

It is important to remember that even though the connection between the researcher and participant(s) may be meaningful during the study, the research relationship is temporary. Although narrative inquirers continually negotiate their relationships, I believe that it is especially imperative that narrative researchers be mindful of this connection when they prepare to exit the field. Researchers must move out of the collaborative relationship and negotiate a new way of being in relation with the participants (Connelly & Clandinin, 1990).

Ethics

The process for obtaining human ethics approval for research through the university ensures that researchers act within a code of ethics to protect the rights of the participants and ensure their well-being (Banister, 2002; Corbin & Morse, 2003). I received ethical approval from the University of Victoria's Human Research Ethics Committee prior to commencing the research. According to the requirements of the committee, participants must be fully informed of their rights prior participating in any research study. It is the researcher's responsibility to ensure that the participants are fully informed prior to obtaining consent. (Appendix F)

Some believe that participants can never be fully informed of the potential consequences because of the unfolding nature of qualitative research (Corbin & Morse, 2003). I believe that if researchers approach the inquiry process with authenticity, sensitivity, and intuitiveness and remain alert and responsive to the shifting and changing nature of ethical issues within the process, it is possible to collect data while protecting the rights and well-being of the participants (Banister, 2002; Corbin & Morse, 2003).

Initial Contact: Entering the Field

The first conversation with each participant is very important. It functions as a part of the initial selection process and sets the stage for developing trust. My first connection with potential participants occurred when interested mothers of children who have undergone the CI process contacted me in response to letters that the resource centre had sent out.

During the initial conversation by telephone with the potential participants, I introduced myself, informed them that I am the mother of a child with a CI, and explained the research project, my query, and my intention. I then verified the appropriateness of each potential participant—which is known as *purposeful sampling*—by establishing whether they fit the criteria that I have previously identified (Creswell, 1998; Sandelowski, 1995). Next, I discussed my role and responsibilities as the researcher and those of the participants, including the time that they would need to commit to the inquiry process, and confirmed that the person was willing to participate (Clandinin & Connelly, 2000). I used this time to start the process of relationship building by developing a rapport with each participant. We also set a date for a face-to-face meeting during the initial telephone call.

Planning the Meetings

I scheduled meetings according to the participants' needs as much as possible. Creating a caring space is very important in NI research to foster feelings of connectedness and mutual respect (Corbin & Morse, 2003). I wanted each participant to be as relaxed and comfortable as possible during our time together and suggested that the meetings be held at her home. If this was not possible, we would select a jointly agreed upon alternate location. Three of the interviews were conducted in the participants' homes, and one interview was conducted over the telephone. I audiotaped all of the interviews with the participants' permission.

Each meeting lasted approximately 1.5 to 2 hours. To minimize potential interruptions, I asked the mothers to arrange for childcare for the duration of the interview time. To compensate them for any inconvenience related to their participation, I offered to pay them \$25.00 per interview. For three of the four interviews the participants' children were present, which resulted in the occasional disruption during the interview.

Interviews

Because of the relational nature of the NI process, I chose to use an unstructured interactive approach to the interviews, which are referred to as open-ended or narrative interviews (Corbin & Morse, 2003). According to Corbin and Morris, this approach presents opportunities for reciprocity because the researchers and interviewees come together to create a context of conversational intimacy, and the interview is therefore an exchange or sharing of experience. An unstructured interactive approach allows the participants to control the course of the interview in that they determine where to start,

what to include or exclude, how detailed the interview is, how they tell their story, and the order of events (Corbin & Morse, 2003).

It would be presumptuous to imply that researchers exert no control over the interview process. The way that an interviewer acts and responds in an interview shapes the relationship and therefore the way that the participants respond and give accounts of their experience (Clandinin & Connelly, 2000; Corbin & Morse, 2003). By virtue of their status, researchers always have a certain degree of power over the interview situation. Corbin and Morse recommended that researchers share information about their lives and explain why they have an interest in the research to help reduce the status differences. Oakley (1990) believed that “interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship” (p. 41). The nature of the unstructured interactive interviews enabled me to share something about my experiences and myself with the mothers. The following reflexive journal excerpt describes how this type of sharing impacted the research relationship and interview.

She said she felt a connection with me by virtue of our shared experiences...that I really understood and knew what she had been through, that talking with someone was great. This level of connection didn't occur – wasn't established until *I* started talking more, divulging more about my experiences – how they were the same, different.

Hall and Stevens (1991) proposed that conscious monitoring of power dynamics during the interview with the intent of mutuality and honesty helps to reduce power inequalities. I consciously and deliberately attended to the issue of power dynamics through reflexive journaling. I wrote:

I must think of ways to elicit emotional remembering in my participants – not just the superficial telling like I had done in my personal writing...I think questions such as “How did this make you feel” or “How do you feel about that” can bring a

deeper emotional remembering. I must be careful too – they may choose to inhibit a particular ‘self’ – one that they/she does not want to make public, that most intimate version of the same story. This way too will help me to respect her subjectiveness.

It is important to approach an interview situation with the intent of hearing stories and to invite the participant to tell her or his story (Chase, 2003; Emden, 1998a).

Although I wanted the women to tell their stories as they wished, I recognized the need to create a detailed interview guide to help them tell their stories (Riessman, 1993). Paying close attention to the details of stories can encourage participants to express themselves fully, and I therefore recognized that I needed to ask questions grounded in the mothers’ everyday experiences (Chase, 2003). I prepared an interview guide (Appendix G) with questions that invited the mothers to tell their stories and helped me to stay on track with the phenomenon of interest by redirecting the participants to focus on their experiences when they began to digress.

Transcription

Once an interview was concluded a transcription of the audiotape was created. Transforming recorded interviews into written text is a representational process of rewriting that is both interpretive and constructive (Riessman, 1993; Wellard & McKenna, 2001). Riessman suggested starting with a rough transcription to capture the words and returning later to add more detail. Textual information is only one component of the interview transcript; it is also important to include nonlexicals such as pauses, sighs, stammering, and laughter, as well as facial expressions and body language (Chase, 2003; Wellard & McKenna, 2001). The way that a story is told provides clues to meaning; thus listening for ambiguities in language, cadence, and volume of voice is imperative (Riessman, 1993). When interviews are transcribed in this way, interpretive

categories may emerge, and it is important to write these thoughts down as they become known so that they may be used later in conducting a more in-depth analysis. Examples of categories included feelings described by the mothers such as guilt, looking for help and descriptions of the child as vulnerable, fragile and dependant.

I invited the mothers to read their own interview transcripts and make changes as they saw fit. They had the option of deleting specific statements or including additional information that they might have recalled after the interview. I e-mailed each participant her interview transcript with an invitation to make any changes that she wished. I also telephoned each mother to ensure that she had received her transcript. None of the mothers made any changes to the original interview transcripts.

Field Texts and Research Texts

Field texts are all things that are used in the interpretation and analysis of the research study; it is an NI term that others may call *data* (Clandinin & Connelly, 2000). Field texts can include anything that a participant uses to tell his or her story: oral accounts of stories, conversations, journal writing, field notes, letters, documents, or photographs.

According to Clandinin and Connelly (2000), field texts are not constructed with a reflexive intent and thus have a recording quality. They are descriptive and can be thought of as memory transformers or memory signposts. However, these authors stated that all field texts are inevitably interpretive texts “shaped by the selective interest or disinterest of researcher or participant or both” (p. 94). They argued that when selectivity occurs we must remain aware how certain aspects are placed in the foreground and others are made less visible.

Where field texts are selective reconstructions of field experience that embody an interpretive process, research texts are at a distance (Clandinin & Connelly, 2000). In keeping with Clandinin and Connelly's thinking, matters of voice, signature, narrative form, and audience must be considered as research texts are composed. The voices are those of the participants, the researcher, and everyone for whom the text speaks. Signature is closely connected to voice. For the researcher it involves finding a way of saying what she or he has to say and a way of being in the text. According to Clandinin and Connelly, being there in the special way that marks each of us as a writer constitutes our research signature.

Researcher's Journal and Reflexive Journal

A field note journal is a tool that researchers typically use to record information specific to the research inquiry (Clandinin & Connelly, 2000). Researchers use reflexive journals as a tool to reflect on subjective thoughts and feelings that they experience during the research process; it situates the researcher and his or her knowledge-making practices within relevant contexts (Finlay & Gough, 2003). A reflexive approach acknowledges a researcher's assumptions about the situated nature of the research, appreciation for the relativity of truth, and willingness to make values explicit and helps the researcher to demonstrate the trustworthiness of his or her findings (Finlay & Gough, 2003; Hall & Stevens, 1991).

Reflexivity is a hallmark of excellent qualitative research and it entails the ability and willingness of researchers to acknowledge and take account of the many ways they themselves influence research findings and thus what comes to be accepted as knowledge. Reflexivity implies that ability to reflect inward toward oneself as an inquirer; outward to the cultural, historical, political and other forces that shape everything about inquiry; and in between researcher and participant to the social interaction they share. (Sandelowski & Barroso, 2002, p. 216)

Because of the relational nature of NI, I found myself with/in the research process in such a way that I considered all journal writing reflexive. My subjectivity influenced every decision, observation, and comment on or for the research, and it was not possible to separate research inquiry notes from subjective comments; therefore, I recorded all aspects of the research within one journal.

I recognized that my multiple roles, including nurse, educator, graduate student, single parent, and mother of a child who has had an implant for eight years, would have implications for my research work. It was important for me to explore and establish an understanding of my perspective from which I could consider my experiences and the experiences that the mothers recounted in their stories (Banister, 1999). I gained this understanding by writing in my journal about my closeness to the topic and reflecting on the intricacies and tensions of this closeness throughout the research process (Banister).

I was aware that my personal subjectivity related to the phenomenon of inquiry acted as a lens that framed my questions and influenced how I later viewed the stories. Therefore, it was important that I identify my knowledge, skills, and intent before I conducted the interviews (McKay, Ryan, & Sumsion, 2003). Thus, I recorded in writing my intent for pursuing this particular study, my personal experiences with cochlear implants, and my experiences with the research process.

The reflexive journal provided a safe environment in which I could reflect on my presence in the field and explore and clarify how subjective elements such as my assumptions, feelings, biases, and anticipated outcomes might have influenced the research (Banister, 1999; Finlay & Gough, 2003). According to McKay et al. (2003), reflexivity requires time, thinking, space, and engagement; and I stepped out of the interpretive process to reflect on my biases and assumptions, took time to contemplate

what was occurring, and revisited my own position. My central assumptions are stated in chapter one.

I chose to follow the reflexive method that McKay et al. (2003) suggested in conducting interviews, in which self-reflection occurs before, during, and after the event. I was therefore able to locate myself in my research, contemplate on what occurred, and explore my thoughts and feelings on the experience and the research process.

During an interview the interaction between researcher and participant is the focus. McKay et al. (2003) advised researchers to be aware of what is occurring; specifically, to examine how they interact with the participants and potentially influence the process.

I anticipated that while I was in the midst of conversing with the women, because of the nature of the interactive interview, I would not stop to take notes, and I relied on my memory to record these impressions. To ensure accuracy, I used the time immediately following each interview to write my observations and interpretations. Later I used verbal cues from the tape recording to add further notations. McKay et al. (2003) suggested that researchers also return to these writings with the transcripts and retrospectively examine the experience. As I reread these field texts, I recognized that these steps encourage a more in-depth reflective process (McKay et al., 2003).

Because I was an insider with respect to the culture I was researching, it was important that I remain aware of how the research process could affect me personally. I anticipated that the act of engaging in the research process would lead to greater consciousness of self as it has for other researchers (Banister, 1999; Clandinin & Connelly, 2000). I remained aware of the need to recognize if or when I became

emotionally distressed during the research process and reflected upon such feelings and responses in my journal.

Analysis and Interpretation

The processes of data collection, analysis, and interpretation often occur simultaneously during qualitative research (Jacelon & O'Dell, 2005; Sandelowski, 1995). However, analysis makes interpretation possible (LeCompte, 2000); it is a means to knowledge production that involves processes of breaking down, examining, comparing, conceptualizing, and categorizing data (Jacelon & O'Dell, 2005). Interpretation is the knowledge produced or created from the data analysis (Sandelowski, 1995).

In considering how to analyze and interpret the field texts, I drew from a variety of narrative research examples (Chase, 2003; Clandinin & Connelly, 2000; Emden, 1998a; Fraser, 2004; Morrow, 2005) and used an adaptation of Fraser's work to explain the stages involved in the analysis and interpretation process. These activities were not linear; the written explanation of these steps is only a representation of activities that have most certainly overlapped (Fraser, 2004).

It is important to affirm that I am not proposing that my reading or interpretation of a story is *true*; rather, it is one possibility among multiple others (Fraser, 2004). I bring my culture, language, experience, and expectations into my interactions with others and with the text. According to Lieblich et al. (1998), even if I wanted to be a *naïve* listener, my attitude towards a participant and my values permeate my reading.

Interpreting what is said is a kind of listening skill. Hearing what someone is communicating is a matter of slowing down and listening again and again to the stories (Chase, 2003). Stories have a social dimension that brings out further meaning and a plot

that gives the story a point. Stories also reflect broad social, cultural, ideological, and historical forms (Chase, 2003; Clandinin & Connelly, 2000).

All stories have either an actual or an imagined listener or reader and are thereby created in a relationship (Frid et al., 2000). In analyzing data, it is important to consider what both the participant and the researcher have said (Murray, 2003). This interpersonal focus recognizes the importance of considering the research relationship and how it informs the (re)telling of the story.

Phase 1: The Interview

During the interview a participant tells his or her story(ies). Because this is a relational activity, the researcher helps to shape the telling of stories by responding in certain ways, such as smiling, encouraging, empathizing, questioning, or clarifying, which ultimately influences the formation of the stories (Clandinin & Connelly, 2000; Fraser, 2004).

One of the first stages of the analysis and interpretation process involves listening to the stories and experiencing emotions during the interview (Fraser, 2004). Consequently, during the interview I was attentive to any emotions that the discussions stimulated, and I noted the feelings that the participants depicted or described, as well as their body language. I then reflected and noted my own emotions evoked during the interview conversation.

Directly after the interview I wrote my impressions of how each interview started, unfolded, and ended. I also reflected on my sense of and overall feelings about the interview.

Phase 2: Creating Written Text From Stories Told

Transforming recorded interviews into written text is a representational process of rewriting that is both interpretive and constructive (Riessman, 1993; Wellard & McKenna, 2001). Decisions need to be made about how to represent the stories and what to include or discard from the interview (Fraser, 2004). Clandinin and Connelly (2000) reminded us that selectivity is important throughout the research process and that when we foreground certain aspects, others in turn become less visible.

A professional transcribed the interviews into written text, and I then added notations to indicate pauses, sighs, and laughter. While I was making these transcription checks and changes, thoughts and ideas began to emerge. I recognized these initial interpretations as potentially the start of interpretive categories and wrote them down to use later in a more in-depth analysis (Poirier & Ayres, 1997; Riessman, 1993; Wellard & McKenna, 2001).

Phase 3: Listening in Different Ways

Once the transcription was complete, I listened to the taped interview several times while reading the transcript at the same time. The intent of the first reading and or listening was to fully grasp the content (Emden, 1998a). Because the *way* that a story is told provides clues about meaning, listening for ambiguities in language, cadence, and volume of voice is essential (Riessman, 1993). I wrote interpretive comments on the transcripts as needed, listened for storylines and main points of the stories, and identified contradictions in the content or manner in which a story was told (Chase, 2003; Clandinin & Connelly, 2000; Fraser, 2004). I also concentrated on identifying gaps, silences, repetitions, or tensions (Chase, 2003; Clandinin & Connelly, 2000; Fraser, 2004; Poirier & Ayres, 1997). Examples of such notations included a) 'time' - the mother's frequently

referred to time in many contexts, b) a sense of helplessness and loss of control, c) having to take on different roles, d) the notion of difference or being different (themselves and the children). One mother would just start getting close to deeper rememberings and feelings and abruptly change the topic indicating that there was potentially some tension and issues that she was not prepared to face. Another mother made assertions such as “The bottom line...” One mother contradicted herself when saying that she did not have support then later talked about all of the people who helped and supported her child. This suggested to me that her perception of who she saw as supportive varied.

Phase 4: Sorting Field Texts

Sorting the field texts involved combining all field text, identifying and separating stories, and regrouping them. I began by merging all related field texts for each participant, including the transcription, journal notes, field notes, and my analytic memos to that point (Morrow, 2005). I spent a great amount of time immersed in the various data to ensure that I thoroughly understood the participants’ experiences (Morrow, 2005).

I then worked to separate the long chunks of talk into specific stories by rereading everything to identify individual stories. This activity can be difficult because people often jump around in telling personal stories (Fraser, 2004). At this point I numbered each line for ease of referencing and identifying specific passages (Fraser, 2004). I then divided the stories into story segments, which are pieces of text that exemplify the main focus of the experience conveyed in the story (Priest, Roberts, & Woods, 2002).

I regrouped related story segments by comparing and contrasting them, and these groupings eventually emerged into informal categories that I call *story groups* (Fraser, 2004). To more clearly understand the story groups and how they potentially related to

each other, I created a large diagram or conceptual map (LeCompte, 2000). I then repeated these steps for each interview and related field texts.

Phase 5: Reading in Different Ways

Reading in different ways involves asking questions of the text from different foci while looking for meaning in the stories. I began by asking two questions: What is the main idea or point in the story? What is this person doing or communicating (especially if it is different from what she is saying)?

Broad cultural assumptions and institutional, organizational, and discursive environments all influence and shape stories (Chase, 2005). With this in mind, I considered how culture, social resources, and circumstances may have enabled or constrained the stories (Chase, 2005). Chase (2003, 2005) maintained that to do this, researchers must have the ability to hear how individuals constantly use, make sense of, resist, or transform those cultural resources and constraints. To accomplish this, I considered the following questions: What taken-for-granted assumptions are evident in the stories? What are the dominant cultural narrative/discourses located in the stories (e.g., mothering, disability, gender), and how do they influence the story (enable, constrain)? Do the stories fit within the typical story forms found within the dominant ideologies of the culture? Are there differences or conflicts in the mothers' experiences from these dominant narratives/discourses? For example all of the mothers were the primarily care-givers for their child. This supports westerns society's dominant belief that child care is the mother's responsibility. Another example reflects society's view of disability, specifically the mother's desire for normalcy. One mother said that seeing how her child was compared to others her age seem to drive her to carry on, work hard and

push her child to improve. Also the very notion of having a CI could imply that not hearing is undesirable and should be fixed.

Phase 6: A Look Across All Participant's Stories

Our personal stories connect us with larger stories—the cultural narratives—and help to shape our shared meanings, which allows us to be a part of but not fully absorbed into the larger cultural narrative (Emden, 1998b). It is important to recognize that narratives are particular to an individual. However, researchers can use a cultural lens to focus on similarities and differences across narratives and identify patterns during particular times in participants' stories (Chase, 2005). With this in mind, I drew out like patterns, similarities, and differences that I had identified across all of the participants' stories. These were ultimately transformed into three themes that reflected the mothers' experiences. The themes were: struggling with new realities, feelings of uncertainty and isolation, and moving on.

Phase 7: Evoking Social Change

NI may be seen and used as a mode of evoking social change (Chase, 2005). For the individual participant, the act of narrating a significant life event can create a very strong and positive change. However, narrative researchers not only create a space where stories can be told and heard, but they also help to open up possibilities for social change by using interpretive strategies to reveal oppressive dominant narratives (Chase, 2005). By connecting individuals' stories to the broader stories of a group creates a community or collective of stories (Chase, 2005). This collective of stories may be heard farther and wider than they would if they stood alone.

Writing the Research Text

The move from field texts to research texts is a complex process that entails shifting from living stories with the participants to retelling stories (Clandinin & Connelly, 2000). It is here that the stories of the participants merge and, with my own, result in new collaborative stories—a reconstruction of the many to make a richer, more condensed and coherent story (Connelly & Clandinin, 1990; Kvale, 1996).

The responses to questions of meaning and social significance ultimately shape field texts into research texts (Clandinin & Connelly, 2000). In the creation of research texts, issues of voice, interpretive authority, and representation must also be attended to (Chase, 2005). It is important that researchers determine how they will use their voices to interpret and represent the participants' voices.

The findings of a qualitative investigation should illustrate a balance between the researcher's interpretations and supporting quotations from the participants (Morrow, 2005). I have used a narrative strategy to write the research text that Chase (2005) recommended in which the researcher's and participants' voices are connected and separated in a particular way; the participants' stories are presented, and the researcher's interpretations follow. By using excerpts from the mothers' stories I was able to illustrate how my interpretations were grounded in lived experiences (Morrow, 2005).

Criteria and Strategies for Achieving Quality

Qualitative research is a very broad term that refers to numerous widely differing research methodologies, many of which include an assortment of criteria to evaluate the quality, or rigor, of a study (Morrow, 2005; Sandelowski & Barroso, 2002). Emden and Sandelowski (1999) and Morrow (2007) recommended that the criteria for judging the quality of qualitative studies be particular to the approach and the paradigmatic

underpinnings of the research. Rolfe (2004) also suggested that each research methodology, and perhaps each individual study, be appraised on its own merits because of qualitative paradigm multiplicity.

In creating criteria to judge the quality of NI, it is important to consider the nature of narratives, to remember that people often change their stories from one telling to the next, and to keep in mind that every human experience, and thus story, is unique (Emden, 1998a; Sandelowski, 1986). Evaluating the quality of a study that uses a social constructivist approach requires that some of the tenets pertaining to this approach be considered. These tenets are mentioned earlier in Chapter One in the theoretical perspectives section on page 2.

To evaluate the quality of this study, I chose the four primary criteria for qualitative research that Whittemore, Chase and Mandle (2001) proposed: credibility, authenticity, criticality, and integrity. They also suggested the use of secondary criteria to “provide further benchmarks of quality” (p. 529), which tend to be more flexible and study-specific. The following section is a discussion of each of the four primary criteria as they apply to this study, as well as the secondary criteria of vividness and thoroughness.

Credibility

A study can be called credible when the data have been interpreted accurately to reflect the experiences of the participants in a believable way (Whittemore et al., 2001). The researcher must make a conscious effort to show that his or her interpretations are accurate and trustworthy (Whittemore et al., 2001). In this study one of the strategies that I used to ensure credibility was multiple data collection, which included in-depth

interactive interviews, field notes from the interviews and from the initial telephone calls with each participant, and my reflexive journal.

According to Sandelowski (1986), because truth is subject oriented in qualitative research, the truth value resides in the discovery of experiences as the individual lives and perceives them. Confirmation of the findings helps to determine that the interpretations reflect the experiences of the participants (Whittemore et al., 2001). To determine that my interpretations reflected the experiences of the participants in this study, I shared my findings with the participants and invited their feedback.

Morrow (2005) suggested, “True value of the evidence is most critical and involves [the researcher’s] building sufficient trust and rapport with the participants [so that he or she] is assured that the participants are telling the truth as they know it” (p. 256). I believe that, given the participants’ comfort in sharing their stories, we had established good rapport through the telephone conversations and interactive, in-depth interviews. Further, my position as a nurse researcher and my comfort with emotions and reactions contributed to my ability to access the participants’ accounts, which for them were at times uncomfortable (Leslie & McAllister, 2002).

Another technique that I used to strengthen the accuracy of my interpretations was to include numerous excerpts from the participants’ stories in conjunction with my interpretations (Whittemore et al., 2001).

Authenticity

Authenticity is closely related to credibility and attends to similar concerns regarding whether the research reflects the meanings and experiences of the participants (Whittemore et al., 2001). More specifically, authenticity attends to the concern that each participant’s voice will be heard.

Issues with the researcher's influence also affect authenticity (Whittemore et al., 2001). According to Lincoln and Denzin (1994), the involvement of the researcher in the research process, specifically being in relation with the participants as well as with the phenomena under study, can influence his or her ability to speak authentically in terms of others' experience. Any influences the inquirer potentially has upon the inquiry must be consciously attended to such as I have done through reflexive journaling as discussed earlier in this chapter in the researcher's journal and reflexive journal section on pages 39 to 41 (Whittemore et al., 2001). Matters of researcher subjectivity and representation as they relate to this study are discussed below.

Subjectivity is valued in qualitative research. In following a social constructivist perspective, I embraced my position as researcher and co-creator of meaning as integral to the interpretation of the data (Morrow, 2005).

To demonstrate that the findings were grounded in and from the participants' perspectives, it was important that I explicate the ways in which I addressed my subjectivity. These included (a) articulating my implicit assumptions and biases to myself and others, and (b) attending to the issues of reflexivity and representation.

At the inception of this study I began writing a list of my assumptions to enable some level of transparency. I revisited and expanded the list throughout the research process and have included it as part of this study report. I also attended to some of my biases and assumptions by engaging in a reflexive process throughout the study. I maintained a reflexive journal, which enabled me to write about and reflect upon my experiences and reactions as well as any assumptions or biases that emerged during the research process.

Issues of representation attend to questions regarding whose reality is being represented in the research (Morrow, 2005). It is considered impossible to separate the researcher from the researched. Rather, what needs to be addressed is how to fairly represent the experiences of the participants (Morrow, 2005). The strategies that I used to represent the participants' realities fairly included (a) asking for clarification during the data-collection process, (b) using techniques that encouraged the participants to look deeply into their experiences (open-ended questions, reflective listening, focus of feelings), and (c) approaching each participant and each story with the view that each is unique in and of itself (Morrow, 2005).

Criticality

To ensure the quality of a study, researchers must include evidence of critical appraisal by using a systematic research design (Whittemore et al., 2001). I have included a detailed explanation of the methods that I used in this study to enable a critical analysis of all aspects of the inquiry.

Researchers also need to engage in critical analysis in their search for different meanings, ambiguities, and biases pertaining to the data (Whittemore et al., 2001). I engaged in such critical analysis throughout the entire research process.

Another way to substantiate criticality is to ensure that the participants' stories corroborate the researcher's interpretations (Whittemore et al., 2001). I have used numerous segments from each participant's stories to demonstrate her experiences and substantiate my interpretations.

Integrity

Integrity is closely associated with criticality. Integrity must be demonstrated in the process of interpretation to ensure that the findings are valid and grounded within the

data (Whittemore et al., 2001). One strategy that I used to address integrity was to ensure transparency of the research process, as I discussed in the criticality section above.

Another strategy to ensure that my interpretations of the data were accurate involved returning repeatedly to the data and spending time deeply immersed in them. The final strategy to ensure integrity was to present the findings in a way that assure a balance between the stories of the participants and my interpretations.

Secondary Criteria: Vividness and Congruence

I selected the secondary criteria of vividness and congruence to support the four primary criteria in considering the evaluation of research quality. Vividness involves the clear presentation of rich descriptive data in a way that portrays the essence of the phenomenon without overwhelming the reader (Whittemore et al., 2001). I believe that I have portrayed rich descriptions of the participants' stories in the story segments that I have incorporated into the text.

The other secondary criteria used to determine quality is congruence. According to Whittemore et al. (2001), this refers to the relationships between the research question, the method, and the findings; between the data collection and the analysis; and between the current studies and previous studies.

NI is congruent with a social constructivist paradigm. The intent of this research was to learn about and understand the experiences of mothers whose children have undergone the CI process. The central concepts of NI include narrative, experience, and story, each of which fits with the purpose of this study. I believe that the study findings present a clear and rich description of the participants' experiences. I collected, sorted, and analyzed the data consistently to discover unique individual experiences (multiple perspectives)—those that appeared shared or similar as well as those that were different.

Although the CI process is well documented, very few studies have explored parents' experiences during their child's CI process, and few of these have used a qualitative perspective. Some of the mothers' accounts of, for example, experiencing grief, having a positive outlook, and feeling isolated have been reported in other research and in other contexts. I have used some of this literature to substantiate my interpretations of the mothers' experiences.

CHAPTER FOUR: FINDINGS

Considering a Three-Dimensional Narrative Inquiry Space

The themes that emerged from the analysis convey the complexity of the mothers' experiences. Understanding mothers' experiences narratively means considering their experiences in terms of a three-dimensional inquiry space: along temporal and personal-social dimensions, and within place (Clandinin & Connelly, 2000). In this introductory section of Chapter Four I will describe how I narratively wove together the mothers' stories or how their experiences, which I categorized into three themes, overlapped. This will be followed by a description of the three themes that emerged from the mothers' stories: struggling with new realities, feelings of uncertainty and isolation, and moving on.

As I considered how to convey the mothers' experiences in a way that would demonstrate the complexity and fluidity of the three-dimensional inquiry space, I reflected on the moments that I spent with each. Our conversations occurred in their homes; I was nervous, and they were unsure of where to begin. During those shared moments the mother and I were living in the midst of being mothers with children who had had a CI while at the same time remembering when and how we came to be there. The co-construction of our interactions during that moment influenced how each of the mothers retold her story. The mothers moved through time as they re-created their stories, and their past experiences and the multiple possibilities of the future influenced how they remembered and retold those experiences in the present.

Even though the study was focused on the mothers' experiences as their children went through the CI process, each began her story by recalling her child's initial diagnosis of a hearing loss. In talking about their experiences, the mothers moved back and forth from remembering the past to talking about the present to considering the possibilities of the future.

Many of the experiences that are represented in the three themes occurred simultaneously. The mothers were immersed in a new world full of possibilities that they had never considered in their past realities. While they were feeling the shock, grief, and guilt, they were often also experiencing feelings of uncertainty and isolation. During these times they were actively searching for information, making decisions, and working toward figuring out their role in this new way of mothering a child who is deaf. At times the mothers felt supported in some ways, while at the same time they felt unsupported and alone. The ambiguity of the mothers' experiences was evident throughout their stories.

NI also considers the personal and social dimension by looking both inward and outward (Clandinin & Connelly, 2000). Many factors such as genetic disposition, the environment, and our experiences during a lifetime shape the person that we become. In considering the personal, we look inward. To look inward at the mothers' internal conditions, I focused on their feelings, hopes, and reactions, both declared and implied in their stories. The social aspect considers who we are, whom we are with, and how we have been influenced by the culture in which we are raised and currently live. For example, a mother's perception of her child's disability may be influenced by the perception of disability in her culture. A mother's past experience with disability and the

perceptions and reactions of those around her can also influence her perception and reaction to her child's disability.

Looking outward means looking toward the existential conditions or environment (Clandinin & Connelly, 2000). While they told their stories, the mothers traveled to many different places and times. Their experiences were located in a variety of places, including their homes, their communities, the BC Children's Hospital, and the paediatric CI center. We may also consider BC, Canada, and Western society part of the mothers' existential environment.

The following three themes emerged from the mothers' stories.

Theme 1: Struggling With New Realities

Woven throughout the mothers' stories are descriptions of struggles. For each of the mothers a change had taken place when she learned of her child's deafness—a change so large that it had the potential to affect every part of her world. In essence, everything in her life had shifted, from how she saw herself and her child to her interactions with others. According to Allegretti (2003), parents typically adapt their entire lifestyle to accommodating the needs of their hearing impaired child.

Some of the struggles were depicted in a variety of experiences related to having a deaf child with a cochlear implant. Occasions on which the mothers struggled with new realities particularly stood out and included reacting or responding to the initial diagnosis of deafness, negotiating the new role of mother, watching her child struggle socially, and experiencing her child's surgery; and they felt a plethora of emotions along the way.

Struggling With Her Suspicions: "We Kind of Had an Inkling"

Each of the mothers developed suspicions that something was not quite right with her child's hearing. These suspicions grew to concern for the child, which ultimately

motivated the mothers to seek answers to what the difficulty might be. For all of the mothers there was a defining event that escalated their suspicions. Jennifer said, “There was no reason to doubt our daughter couldn’t hear....One day I realized that she was not turning when I called her.” She described performing a number of small tests at home from calling her from behind to banging pots when she was sleeping, all with no response, “so we kind of had an inkling.”

Michelle recalled balloons popping and everyone jumping except her daughter. “I think deep down inside I knew....She was officially diagnosed at 16 months, but I think I’d known for a long time.”

Colleen remembered hearing a pot dropped between her child and a friend’s son: “He jumped a foot; [my daughter] never even looked up.” It is interesting to note that she had already taken her child to the doctor with concerns about her hearing, which suggests that, like Michelle, she too intuitively knew that something was wrong.

Sara reported:

I just remember my son being born and thinking that he was normal, a perfectly healthy little baby. . . . He just would sleep through anything, and he wouldn’t respond to sound really. And then I realized he didn’t startle when you went up to him, [but] you’d touch him and he’d jump out of his skin. . . . He got tested, [and] the results showed that he was definitely deaf.

This excerpt hints at a change in Sara’s perception of her child from a normal, perfectly healthy little baby to a child who was deaf. I suggest that all of the mothers experienced a similar shift in their perceptions of their children.

Jennifer’s comments reflect her changed perception: “After she was diagnosed with being profoundly deaf, for some reason it made her seem very fragile to me. I didn’t want to let her out of my sight. She seemed very vulnerable.” Colleen also saw her daughter

differently: “She’s more vulnerable than an average hearing child.” The change in how the mother saw her child in turn effected a change in the mother’s perception of herself as a mother of a child who is hearing to a mother of a child who is deaf.

In our society when we have concerns about our health, we typically turn to medical professionals, usually physicians, for help. When the mothers had suspicions about their children’s hearing, they too sought answers from their physicians. Their concerns were often met with disbelief and often disregarded. Seabrook and Rodda (1991) maintained that medical professionals often underrate parents’ concerns, which leads to a delay in diagnosis.

Colleen had taken her daughter to the doctor twice because of her concern about her child’s hearing. She talked about the initial visit: “I asked my doctor about this, and she put it down to ‘first-time-mother syndrome.’ She checked her ears and said, ‘Oh they’re perfectly fine.’” Even though the doctor told Colleen that everything was fine, she still worried:

I said, “There’s just something that’s not right, mother’s instinct.” . . . So we went back a second time and my doctor goes, “Her ears are clear.” And I said, “There’s got to be something; . . . she doesn’t even react!” [The doctor said,] “She’s got selective hearing.” And so . . . I let it go.

This mother listened to her intuitive sense and returned to the doctor with continuing concerns; unfortunately, the doctor dismissed them for a second time. Nelson (2002) suggested that there is often a naïve trust in physicians that eventually lessens as the mother becomes more confident in her abilities.

Jennifer talked about her initial visit with the doctor and told me that she felt she was “armed with more knowledge than a typical mother would have.” She too experienced a physician’s attempt to dismiss her concerns with “No, it’s probably fine.”

She reported, “I had to fight for what I wanted. I convinced him to send me to an ENT.” Two months later when she saw the ENT doctor, she experienced the same disregard for her concerns: “The specialist [was] saying, ‘She looks fine to me, . . . but if you really want it, then I guess I’ll humour you.’” She added, “I was fairly forceful. I wanted a hearing test!” The language that Jennifer used to describe her experiences implies that she was in a battle, fighting for her daughter.

The mothers’ suspicions about a possible problem with their children’s hearing led them to seek help; however, even though they were concerned that something was wrong, they did not consider deafness the potential problem. They often assumed that the condition causing the hearing loss was fixable. Michelle remarked, “When we found out that she couldn’t hear, I thought, It can’t be that major; . . . they’ll fix it.”

The idea that the problem was something other than fluid in the ears or an infection was far from Jennifer’s mind. She recalled becoming agitated in the sound booth during the hearing test: “It was getting louder and louder, but I couldn’t understand why she wasn’t turning to anything.” She saw the audiologist’s face and described having a “sinking feeling. . . . I knew that second there was something majorly wrong.” However, even after the audiologist told her that her daughter had “a significant hearing loss,” she was “still thinking there’s something that can be done. . . . I still wasn’t understanding.” To help her to comprehend the depth of the problem and its ramifications, the audiologist had to tell her directly: “Your daughter is deaf. She’s going to require special help at school, and she’s going to require it for the rest of her life. You’re not going to be able to fix this.”

“There’s No Way This Is Happening to Me”

One mother’s response to her child’s initial diagnosis of deafness was, “There’s no way this is happening to me.” A child’s diagnosis of deafness is typically shocking and unexpected to hearing parents (Seabrook & Rodda, 1991). The literature has shown that shock, confusion, and disbelief are common reactions to the initial stages of discovering a disability (Nelson, 2002). Jennifer described feeling “like a train had just whammed into me. . . . I was shaking and could barely drive home.” She further described it as a “feeling in your gut, raw emotion, . . . a feeling of disappointment and upsetness.” As she continued her story, it was obvious that the experience was overwhelming: “I felt like a bottle with a cork in it. You know, if someone grabbed the top, everything would just come pouring out.”

Michelle described the experience of receiving her child’s initial diagnosis of deafness as “devastating. . . . I remember I would sit in the bathtub and cry my eyes out. . . . I thought, You’re never going to hear me say ‘I love you’; I’m never going to hear her say ‘I love you mom.’” Her anguish and grief were palpable. Grief is a natural human response to a significant loss (Blaska, 1998), and in this case the mother may have been grieving the loss of the normal child, the hearing child.

Like other mothers, Colleen also had a physical reaction to the news: “I felt like I’d been hit in the stomach and it was just punched. . . . this whole thing was overwhelming.”

You expect your child to be perfect, and I know it’s a dumb word to use, but no issues. Then all of a sudden this is thrown at you, and you don’t expect it and you’re just stunned. . . . I would cry; I was just really emotional. This was my child, you know, and I didn’t know anyone who had a deaf child. What are we going to do? What are our lives going to be like? I’m still like, Why did this happen?

There was great uncertainty, confusion, grief, and sorrow in this new reality of having a child who is deaf (Allegretti, 2003; Seabrook & Rodda, 1991).

Sara seemed to be better prepared for the diagnosis of her son's hearing loss because she had already experienced the shock of receiving similar news when her first child was diagnosed with a hearing loss:

It was easier for me to deal with [my son] because [my first child] laid the groundwork [when she was diagnosed with a hearing loss]. . . . I think I had a pretty good prep to go through. With [my first child] it was different; it was harder for me.

Sara recognized that she had struggled when her eldest child was diagnosed. When she went through it the first time, she experienced similar reactions to those that the other mothers in this study experienced. However, her son's situation was different from her daughter's because he was completely deaf, and this changed everything. Sara stated, "He was deaf and, oh, goody, here we go down a different road that I wasn't planning on taking."

Mothers commonly express feelings of guilt when a child is newly diagnosed with a disability (Nelson, 2002). Jennifer described her anguish at having missed something so important in her child that she felt she should have known. She described being "plagued by guilt. . . . I felt so guilty that I had missed it for 12 months. . . . How could I have missed her being profoundly deaf? I felt so stupid." This speaks to the enormous pressure that this mother placed on herself and the responsibility that she felt as a mother.

Colleen also described feeling guilty because she thought she had somehow caused her child's deafness:

I was so stunned from the results of her being deaf that I was trying to think of what would have caused it. What I did do wrong? . . . It was like, Oh my God!

And there was no history; it was my fault; I did something when she was in the womb.

It is interesting that all of the mothers knew what had caused their children's deafness; they had made a point of finding out the cause. I believe that knowing the cause helped them to understand and possibly to move on.

For some the guilt never goes away. One mother said, "It's still there, still there; I still feel it. Oh yeah, there's times where when I'm alone and I think, you know, that . . ." This unfinished sentence, then a sudden change of subject, speaks volumes to the difficult times and emotions that this mother still experiences. I believe that grieving is closely tied to the continuing or recurring feeling of guilt. Grief can often last throughout the lifespan and become what has been called chronic grief, chronic sorrow, or nonfinite loss that can be reexperienced at any time (Blaska, 1998; Bruce & Schultz, 2002; Reisz, 2004).

The Anguish of Being Different: "It Just Kills Me"

The mothers' stories revealed their feelings of grief, anguish, and sorrow in many of their experiences that were often triggered by situations that reminded them of their children's differences because of their deafness. Michelle referred to it as "always a reminder of where they're at compared to where they would be if they could hear."

The mothers talked about being reminded of their children's differences and how far behind they were when they saw younger children doing things that they thought their children should have been able to do. Jennifer said, "It takes [me] back to the beginning."

Sara described how such reminders have affected her:

There's a part of me that just sinks. . . . It's kind of, Wow! This kid— . . . You just recognize it all of a sudden. I don't get it until I'm around somebody else's kid, so I don't really do much with someone else's kids. And I think maybe part

of that is because I don't want to recognize how behind they are. . . . I have sinking feelings at least once a day. I think it's an ongoing thing, and you just a little bit a day feel sorry for yourself and feel sorry for them and feel the hurt and go on to the next one.

This mother's pain was so intense that she was avoiding other children to keep from being reminded of her child's differences. In the quotation above she described her continuing sadness and pain, which suggests that she was experiencing chronic grief (Luterman, 2003). According to Luterman, we feel chronic grief on a daily basis as a result of being constantly reminded of a loss.

Reminders of differences also came from the mothers' recognition of something that they missed or were anticipating missing. One mother explained, "Seeing newborn babies, I recognize their response to sound, and that makes me sad because . . . I never had that. So there are parts that hurt." Two mothers talked about how they had been sad because they believed they would never hear their child's voice and that their child would never hear her say "I love you".

Mothers typically want their children to fit in, make friends, participate, and have fun. Sara acknowledged this wish and voiced her concerns:

You want them to fit in and you want them to have good friends. You have to recognize what kind of social struggles they have, and I think that's the big social aspect. You don't want them to get picked on, and bullying is a huge part of any parent's worry. And you think, Oh, you've got a red-flag target on your back!

Jennifer talked about her child's not fitting in:

She's in no-man's-land. She's not really part of the hearing world or a part of the deaf world. We have sort of pushed her into a category that is really a no-man's-land. She sort of has no people. She's not comfortable in her own skin, and the only place that she's extremely comfortable is at home. . . . Sometimes she'll say, "I don't fit."

Watching her deaf child struggle in social situations often resulted in strong emotional reactions from Jennifer. She related examples of such struggles:

She's also had troubles with relationships. You know, a lot of little girls are impatient. They want to talk fast; they don't want to listen to her. She has a lot of trouble making friends because of it. It's so sad. . . . She has two cousins around the same age in private school together, and I cannot put her there. It's really, really upsetting because those two are becoming thick as thieves, and [my child] is on the out. It just breaks my heart.

The mothers also found it difficult to see their children struggling in other ways. Sara commented, "I hate to see him struggling. . . . I look at him at age [x] in school and the struggles he's having just trying to speak with the implant." For Jennifer's daughter the struggles in school were getting worse, and this affected both mother and daughter:

She has been the happiest kid out there, but the schooling is getting so much harder for her that it's affecting her whole life. She's starting to be a sad child, and it's just killing me, absolutely killing me to see her sad.

New Realities: "You're Immersed in This New World"

Every part of a mother's world is potentially affected by her child's diagnosis of deafness, including how she sees herself and defines her role as mother. The literature has shown that mothers must negotiate a new kind of mothering, redefine their maternal image, to accommodate their new role as the mother of an atypical child (Helitzer et al., 2002; McGuire, Crowe, Law, & VanLeit, 2004; Nelson, 2002).

Because mothers are often the primary caretakers of their children, the extra responsibilities of caring for a child with a disability typically fall upon them (Nelson, 2002). Michelle's and Sara's comments demonstrate the great responsibility that they felt as mothers of children with extra needs. Michelle said, "Women seem to be the ones who

are always organizing and take on the responsibility. . . . If I'm not up on everything, she would suffer, right? No one wants their kid to suffer, so it's a big burden."

As a mom you feel responsible for everything. You think, These kids aren't going to be failures, and I'm going to do everything I can that's possible to benefit them. . . . You take on the weight because nobody else is going to do it, and then you kind of overfunction. (Sara)

Raising any child can be challenging, but when the child has a special need, this task may seem overwhelming (Luterman, 2003).

Mothers of children with disabilities often have to assume many different responsibilities, even those usually performed by therapists (Helitzer et al., 2002). CI is a lengthy process of which re-habilitation is the most extensive and demanding phase (Most & Zaidman-Zait, 2001). Parental involvement in the re-habilitation phase is essential and typically falls to the mother (Russell & Coffin, 1999).

The mothers' stories were rich with examples of experiences in their new role that included the extra work and responsibilities of having a deaf child with a CI. Michelle said, "The time I have to spend with her is definitely different. . . . You become a therapist [because] you have to." Jennifer reported, "I've had to do so much work. . . . I do probably an hour of therapy a night." Michelle spoke about how much she had to learn, how different and difficult it was:

It's different. There was just a learning curve. . . . I knew it would be lots of work. I don't think I realized actually how hard it would be or how long it would take. It takes a while for it to kind of come to that realization and when you start learning about language and how it develops.

She shared an example of how her role was different:

Learning to talk all the time was difficult, . . . repeating everything twenty thousand times over. If loading the dishwasher with a hearing kid I would say, "Give me the fork" and put it in and carried on, with my child, if there was ten

forks in there I would say it ten times: “Give me the fork, give me the fork, give me the fork,” and just over and over and over.

The mothers described feeling pressured to work with their children to help them learn to listen and speak:

I always feel under pressure to get her to—I don’t know—to perform, to practise, to learn. It’s constant, because in reality the window of learning is so short. . . . It takes a considerable amount of time to get your kid speaking, get them listening right. (Michelle)

“Always having an ulterior motive to play” was difficult for Michelle. She added, “I would envy my friends who could just play with their kids.” The reality of deciding to use a CI includes the very limited timeframe within which humans learn oral language when they are prelingually deafened, which adds the pressure of time (Callanan & O’Connor, 1996; Hehar et al., 2002).

The pressure to improve was constant for these mothers and seemed to come from their desire for normalcy. It is typical of mothers of children with disabilities to look for, desire, and, if possible, work toward normalcy (Nelson, 2002):

Seeing other kids to compare her to, but she’s not where they’re at, it just pushes me to want to push her more. It’s hard to draw that line to push but just enough to be positive progress, . . . always trying to be right on that line of being perfect, not being too pushy, but not being too lax. You’re kind of walking that line all the time. (Michelle)

It appears that Michelle was struggling with her multiple roles: a nurturing, caring mother and a therapist who needed to be goal oriented.

Sara also talked about the change in her mother role and the related strain: “Every day is a different day to try and grow and teach and learn. You put so much more into it, and worrying about everything. . . . I don’t want to be their teacher, but I have to be their teacher.” She attributed the pressure to societal norms that she has fought:

You get so pulled into that societal bullshit that you go off to one end of the Richter scale . . . to be an overfunctioning parent. You're trying to do too much, and your child is drained because you're putting too much pressure on him. . . . [But] if you're too lax and they don't do as well as [the teachers are telling] you they should— . . . So it's a constant balancing act as they grow; every day it changes. . . . If you live your life by somebody else's standards, you're never going to be satisfied. You've just got to live the life that you have.

The Surgical Experience

Any surgery is typically a stressful event for parents, and this certainly holds true for CI surgery (Allegretti, 2003). The mother's stories of their experiences with the surgery reflected a time of heightened anxiety and stress:

I was anxiety ridden about the surgery, and it was a long four hours. . . . You think, I'm going to cut open my son's skull, and I'm going to put a magnet in it, and they're going to have to drill a cavity in it. It's a four-hour surgery, and I know what surgery's like, and when you're in there it's not a pleasant thing; it's a risk and it's stressful, and not everything goes as textbooks say it's going to go. (Sara)

Sara's comment illustrates her awareness of the seriousness of what was happening and could potentially happen:

Your curly-locked little boy goes in for surgery, and he comes out and he's a bald little creature, and . . . sedation and drugs and the IV and everything. . . . It was a long night, a very long night, and I felt bad. Like, what did I do to my little boy, right? What the hell was I thinking?

Sara seems to have seen her child in a different way. For her he had come out of the surgery changed, and she struggled with these changes and her decision.

Colleen's anxiety was obvious as she spoke of her experience with the surgery:

We went into the hospital, and my stomach was turning, and I just said to [my husband], "I can't go into the surgery part where they put her to sleep." It's like, "Oh my God! What have I done?" Right?

She questioned her decision over and over: “Am I doing the right thing? Did I make the right decision?” This suggests that she felt overwhelmed by the responsibility of making the decision to implant and putting her child through surgery.

Jennifer also spoke of her fears and anxiety:

I was scared for her life. I was really afraid she wouldn't pull through the surgery. . . . I actually broke down in the hospital when they shaved the side of her head. I'm like, “Oh my goodness, what am I doing? . . . I want her to have a choice, but it's killing me!”

Even though Jennifer knew that she wanted her child to have the CI, she too struggled with her decision:

I wanted her to have a choice, but I knew that I was hurting her to do that. . . . In essence, it was a cosmetic surgery; it was not something that was medically necessary. I had a lot of guilt around that. . . . I felt very guilty, very, very guilty that I was doing this to her. . . . I was killing her deafness; I was doing something that I wasn't supposed to be doing.

The intensity of the experience was amplified when Jennifer initially saw her daughter after the surgery. She described her experience when she entered the recovery room:

I saw tubes coming out of her, and the side of her head was all bandaged, and she was unconscious. . . . My knees just buckled. . . . “I'm going to faint!” And I just ran right out of the room. “Oh, what have I done?”

She said later that she “did not regret doing it, but just felt the consequence of her being in the pain was too great a price to pay.”

Conversely, Michelle did not experience doubt or concern during the surgery:

I was just thankful [she was getting the implant], I wasn't worried that the surgery—I had no fear. It was like once I knew she was getting it, let's just do it, let's go. . . . So she had her implant, and it went really well.

She explained that nothing compared to the stress she felt during the second set of testing in Toronto and while she waited for approval.

The initial activation and programming of the device, also known as *turn-on*, is another significant step in the CI process. During this time parents often have high expectations and experience anxiety because of the uncertainty of the child's reaction (Allegretti, 2003; Zaidman-Zait & Most, 2005). For the most part, the mothers talked about the turn-on as a positive experience. Sara reported, "He had a really good response. It didn't scare him and didn't freak him out at all. It just went really smoothly. . . . He adapted really well to everything." Michelle said:

She looked up with a surprised look. We all kind of laughed and scared the crap out of her, so she started crying. . . . They turned her on, and we left and went to the aquarium after, and she just carried on from that day.

Jennifer told me, "She put her hands up to her face and went, 'Ohh!' . . . [There was] no crying. It was pretty cool; . . . she begged us to wear it. We couldn't get it off her."

For Colleen the turn-on experience was very different; she described it as "overwhelming" and explained, "[The audiologist] hooked everything up said, 'Here we go,' but nothing happened. We're all looking at each other; nothing's happening; it's not working. It's not working!" After making some adjustments, the audiologist tried again:

He hooked her back up again, and as soon as he hooked it back up and switched her on, boom! She just screamed and started crying and ripped it off, and he says, "That's it! That's the response we wanted." And I say, "She's hurting! It's not supposed to be like that!" "And he goes, "Well, it's the way it is."

Things did not go as Colleen had hoped they would:

As soon as he turned it on, I thought she was going to hear us say "Hi" and things would be okay even though we'd seen the video of the kids crying and stuff. "Oh, no, that wouldn't happen" type of thing. "Be prepared for it." But I wasn't prepared for nothing.

Parents typically have high expectations for their child's outcomes even though they may say that they understand all of the uncertainties associated with CI (Zaidman-Zait & Most, 2005). In fact, unrealistic expectations may reduce a mother's ability to internalize information that does not support her hopes, which can result in a disconnect from the information and parents' expectations (Zaidman-Zait & Most, 2005).

Many Areas in Mother's Lives Were Affected: "You Pretty Much Give up Everything"

The new reality of having a deaf child with a CI had changed the mothers' lives in a variety of ways. Many of these changes were directly related to the energy-intensive nature of the role and the time-consuming tasks associated with re-habilitation (Helitzer et al., 2002). According to Nelson (2002), mothers of children with disabilities have typically made their children the centre of their lives, redefined their priorities, made personal sacrifices, and altered their lifestyle to accommodate this new role.

The mother's stories reflected similar experiences. Colleen said, "[I] reprioritized things in my life, which has been her since she's been born, and then of course with the hearing loss, it's been that much more important for me to go and spend time with her."

Michelle talked about her experience:

I think just the stress of having to pretty much be the main orchestrator of anything that would happen. . . . You don't have that time to watch TV or let her play and you relax. . . . I think it took pretty much any time that I thought I would ever have to do anything else. [My time] was kind of sucked up by that. I don't want to seem resentful about it but—

Michelle described what it was like for her when she found life particularly stressful:

[It would be] really, really busy all the time, never having a moment to enjoy life. . . . Life just seems to go by, and you notice it's gone, but you're not really living in it. That's how I feel a lot of the time—not really enjoying the moment.

Sara also talked about the constant busyness of her life: “You’re go, go, go, go, go: Go to work, come home, and work. You can’t sleep cause you can’t shut off your brain once you’re in bed, and you’re overthinking everything.”

When a mother’s time and energy are directed toward caring for her child and ensuring the child’s well-being, it is accordingly taken away from other areas in her life, including self-care (Helitzer et al., 2002; McGuire et al., 2004). Michelle described her experience:

I haven’t done anything for myself really since she’s been born, and . . . I’m trying now to say, “Okay, well, now I can go to the gym. I can do that for an hour; it’s not going to kill her to not be learning or performing all this stuff all the time, right? And let her relax a little bit too.” Yeah, so I’m trying—I’m trying to focus on myself more now too. It’s hard to do that because I keep thinking that I should be doing all this other stuff. . . . It takes us a few years to recognize that you need to spend time on yourself, I think!

It is apparent that Michelle was still struggling with shifting her priorities to include self-care even though she recognized it as something that is important. McGuire et al. (2004) maintained that a mother’s heightened sense of responsibility for her child’s happiness often results in patterns of behaviour that can compromise her own well-being.

Colleen also recognized the value of self-care but had not changed her actions:

I would put [working out] aside to spend time with her, and I’ve been told I have to stop doing that and start thinking more about myself, because once my self-esteem feels better, then I’d be a better person for her as well, a better parent. . . . I actually have three days a week that I can [exercise], but I also have to have the energy to do it and the mindset to do it, and I don’t have the mindset that I used to have.

Mothers of children with disabilities often experience more stress and less psychological well-being (McGuire et al., 2004). When I asked the mothers whether they

felt that their experiences had affected their health and well-being, they replied, “Oh, totally. How could it not?” “Oh yeah, most definitely,” and “Oh, huge.”

Sara described significant changes to her health and well-being as a result of her overall experiences:

I would say that my health has declined 75% to what I used to be like. I’ve had strep throat, pneumonia, bronchitis in the last four years. . . . I’ve been more chronically ill cause I’m so worn down. . . . I’ve never felt as tired as I have been. I can’t remember the last good day I’ve had when I haven’t had some sort of pain or ache or put my back out or just being sick or whatever.

Sara attributed the decline in her health mainly to stress and anxiety: “The anxiety is not being able to sleep or relax or shut things off or have down time and get the rest that you need to recoup for the next day.”

Jennifer had her own perspective on the subject of health and well-being: “I don’t think it has had a ramification in terms of my actual health, . . . [and] mentally the postpartum [issues] had a far more significant impact on my day-to-day life than the hearing loss has ever had.” However, when she talked about her experiences, she described not being able to sleep and eat and feeling sick to her stomach. This suggests that even though she responded to her experiences physically and emotionally, she did not interpret them as having affected her health and well-being.

According to Nelson (2002), the employment status of mothers of special-needs children is also typically affected. Each of the four mothers interviewed for this study had her own unique employment related issue. Colleen was on leave from her job as a result of a previous injury. Michelle decreased her work time outside the home to be able to meet the demands of her new role: “After she was diagnosed we had all the appointments; . . . it was like we were going somewhere every two days.” Jennifer stated,

“I’m full-time at home by choice because I wanted to be there for her, and at the time I felt like she needed me”; whereas Sara was the sole provider for her family and did not have a choice to work or not:

Unfortunately, society doesn’t let the mother stay home and look after your children and get paid for it. Do you give up your job and stay home? Then you can’t feed your children. No, that’s not an option. So you go to work so you can put food on the table, but you can’t do all the extracurricular things that your child needs, and the school’s telling you to do home reading and do math homework and times tables. You work for your children and come home at six o’clock at night and be fed, bathed, brushed, washed, and then two hours of homework on top of it all, and then you’re supposed to get quality time in there somewhere.

It was apparent that Sara was experiencing great strain and stress as a result of being the sole provider and caregiver—the one who was ultimately responsible for everything. She had, in fact, determined that this was an impossible undertaking.

Summary

The mothers’ stories were filled with many struggles as they went through the changes related to their children’s diagnosis of deafness and subsequent cochlear implants. They spoke of times when their suspicions that something was wrong with their child’s hearing was confirmed as deafness and the emotional impact of this. Initial feelings of anguish, grief, confusion, and guilt often returned when situations arose that reminded them of their children’s differences and struggles because of their disability.

The mothers struggled with other changes and transitions, including redefining their role of mother of a child who is deaf and then again of mother of a child with a CI. They spoke of the responsibility and stress that they felt related to these demanding roles and how their lives had been affected in many ways, including the impact on their health and well-being.

The new realities of deafness and CI created new and different complexities and struggles for these mothers. Their lives had been changed in many ways, and they described their struggles with many of these changes in their stories.

Theme 2: Feelings of Uncertainty and Isolation

The second theme that emerged from the mothers' stories concerned their feelings of uncertainty and isolation—the underlying essence of their struggles.

Feelings of Uncertainty

Coping with stress and change have always been fundamental issues for human survival (Williams, 1999). The unpredictable nature of change typically creates feelings of uncertainty (Neill, 2002). When a mother experiences a critical life event, such as her child's diagnosis of deafness, she often struggles with uncertainty (Allegretti, 2003). Feelings of uncertainty were prevalent throughout many of the mother's experiences, including the diagnosis, CI approval, surgery, the potential for different responses to CI activation, and therapy.

Parents are often overwhelmed with a sense of uncertainty when they are confronted with their child's diagnosis of deafness (Allegretti, 2003). Allegretti maintained that parents' uncertainty of living with a child who is deaf often involves many areas of life, including daily routines and activities. She suggested that a family's effort to adapt to their child's impairment will greatly influence the outcome of uncertainty. Nelson (2002) stated that the process of mastering uncertainty implies the ability to move forward and is associated with an increased sense of control.

After learning of her child's diagnosis, Colleen's life suddenly seemed full of uncertainty and questions: "I didn't know anyone who had a deaf child. What are we going to do? What are our lives going to be like? I'm still like, Why did this happen?"

Shock, confusion, and fear are common during the initial stages of learning about a child's disability (Nelson, 2002; Seabrook & Rodda, 1991). At the same time, mothers must also deal with the unpredictability of the disability and the effect of the disability on the child's future (Allegretti, 2003; Kurtzer-White & Luterman, 2003).

Some of the mothers felt uncertainty during the CI approval process from not knowing whether their children would meet the criteria for CI. The decision on whether their children should have a CI and the approval process that the team from the centre used often occurred simultaneously. Sometimes the mothers would have decided to have the implant before the team had designated the family as potential recipients. This was the case for Michelle, but she had to endure the uncertainty of approval twice, the first time with the BC CI program, and then again in Toronto:

[In Vancouver] I started actually hoping that her hearing would be bad enough to get an implant. . . . [It] might sound bad, but I actually was praying that she would be deaf enough to get an implant. . . . We had to go through the whole process of getting it approved in Toronto because they wouldn't take Vancouver's word that she was eligible; she had to be eligible under their hospital rules. So when we went there we didn't know if she could get implants or not, . . . so we had about a week and a half of testing before we knew if they would implant or not, which was probably the most stressful. . . . I just wanted her to fail so bad so that she could get the implant, and we were so desperate. I was just sick; I don't think I've ever been so stressed in my entire life.

These times of uncertainty created great despair and anxiety for Michelle. Many parents have found the assessment period particularly difficult, waiting to hear whether their child would be an appropriate CI candidate (Archbold et al., 2002).

Many of the mothers also had feelings of uncertainty during the surgery. Because any surgical procedure can be a potential risk, there is a level of uncertainty about the health of the child who is undergoing a three- to four-hour CI surgery (Allegretti, 2003). Uncertainty can intermingle with fear and worry about the child's life in terms of the risk

factors associated with anaesthetic as well as the potential complications related to CI surgery. The mothers recognized the CI surgery as potentially dangerous. Sara explained:

I know what the risks are, and surgery is surgery; there are things that happen. They're horrible, but you just hope that your child is going to be part of the norm and not that one per cent that ends up having an anaesthetic risk.

The time leading up to the surgery and the operation itself are very difficult for some parents (Archbold et al., 2002; Weisel, Most, & Michael, 2007). Parents typically experience anxiety regarding the potential development of any one of the many adverse effects or complications associated with CI surgery during the operative period (Russell & Coffin, 1999).

The mothers also talked about feeling uncertain during the initial activation and programming of the CI (the turn-on). Each child can potentially respond differently to the CI turn-on, and there is no way of knowing whether a child will adapt easily or react strongly to the sudden experience of hearing (Allegretti, 2003; Zaidman-Zait & Most, 2005). Luterman (2003) suggested that parents often secretly hope that when the implant is activated, their child will immediately start responding to sound and start talking. Zaidman-Zait and Most reported that parents are often disappointed during this time as a result of unrealistically expecting an immediate change in their child's communication skills.

Michelle spoke of her expectations after her daughter's CI was activated: "I had this illusion [about] after she got implanted. She got turned on September 26, and I thought—it makes me laugh now—I'd have her saying 'Trick or treat' by October 31st!" Michelle recognized her own unrealistic expectations about her daughter's speech development immediately after turn-on. Her experience substantiates the notion that

mothers' expectations are typically high at the beginning of the process (Wiesel et al., 2007).

Uncertainty arose for some of the mothers regarding how their children would respond to the therapy, specifically whether they would learn to talk and communicate effectively with others. CI outcomes are variable because so many factors affect the child's success in using a CI, and there are no guarantees of success (Russell & Coffin, 1999). Michelle's comments reflect similar uncertainties about whether her child would learn to talk and communicate as a result of the rehabilitation:

She can speak and she can hear, so it's kind of like, thank God, really, because you don't really know. You see kids who do really well, and you see kids who don't do well, and you kind of hope that you're on the good side of things. You don't really know; there's no guarantee.

Allegretti (2003) maintained that in most cases uncertainty about whether the device will help the child vanishes after the CI is programmed. However, some parents remain uncertain about whether their child will establish age-appropriate communication skills. This period of uncertainty can potentially last indefinitely because it takes months and even years of therapy for a child to acquire speech (Most & Zaidman-Zait, 2001).

Jennifer's uncertainty arose from the probability that her child had an additional disability, "a true learning disability"; however, a definitive diagnosis had not yet been made. She explained, "It's something to do with the way she's learning. . . . There have been a lot of things going around, saying maybe it could be this, maybe it could be that."

Being in a place of unknowing was difficult for Jennifer:

So I've kind of gone back into the mode of, How do I help her? . . . So we're waiting for February to have this full assessment. . . . I feel afraid for her future; I feel unsure. With this additional learning disability I'm like, What the heck is it and how do I help her?

It seems that a large part of Jennifer's angst and struggle in this new situation was related to the need to make some major decisions about her daughter's schooling. It had been suggested that she move her child from the regular school, which housed a district program for children who are deaf or hard of hearing, to a very different program:

They said, "We need to focus our attention on why [your daughter] is not learning. . . . We will take her out of the regular curriculum and put her into something which is more for a child that is actually challenged mentally as opposed to just physically." . . . It's a huge decision to make at [x] years old. Which means she will never graduate. It's a huge decision to make.

Jennifer was faced with yet another potentially life-altering diagnosis for her daughter, one that would add complexity to her already complex reality of having a deaf child with a CI. The uncertainty of a definitive diagnosis with its potential ramifications created a new level of uncertainty for Jennifer about her daughter's future.

There seemed to be an underlying sense of uncertainty throughout many of the mother's experiences, from the time that they learned that their children were deaf through many of the stages of the CI process.

Feelings of Isolation

Mothers typically experience many different feelings in reaction to their children's initial diagnosis of deafness: shock, confusion, sadness, disbelief, uncertainty, helplessness, frustration, and isolation (Allegretti, 2003; Nelson, 2002; Weisel et al., 2007). Each of the mother's stories communicated a sense of isolation in terms of feeling alone, that no one understood what they were experiencing, that their children were not accepted, and that they were unsupported.

Mothers of children with disabilities often experience both psychological and physical isolation (Nelson, 2002). Psychological isolation is often related to the mother's

perception that people do not understand her situation and experience (McGuire et al., 2004; Nelson, 2002). Psychological isolation may also result when mothers perceive a lack of acceptance of their children from friends, family, and society and when they feel unsupported (McGuire et al., 2004; Nelson, 2002). Physical isolation may be attributed to environmental obstacles such as living far from support services or finding it difficult to get out by themselves (Nelson, 2002). Michelle talked about no one understanding what she was going through:

No one else gets it really. Everyone thinks, “Well, now that she’s [got the implant], it’s fine,” and it’s not that way. . . . You have no freaking idea how much I’ve been working my ass off to get her fine. You know, you’d almost be like, “How dare you say that! Do you have any idea how much work this is?” And I don’t think anybody does. Yeah, no one.

Michelle felt angry when she thought that others did not understand the effort she had to make to help her daughter learn to hear with the implant and learn oral language. Lack of acknowledgment of this effort contributed to her sense of isolation. Feelings of isolation may result when one perceives that others do not understand (McGuire et al., 2004; Nelson, 2002).

Some of Jennifer’s sense of isolation emerged when her child’s language development was not progressing. She felt alone when she felt that no one understood her situation. The educators who worked with Jennifer’s daughter had recently discovered that the child had an “additional learning issue.” Jennifer explained: “She talks like a three-and-a-half, four-year-old, and she’s stuck there. She’s been stuck there for about two-and-a-half years.” She reported that this lack of progress had created many difficulties for the child and, in turn, for her: “I don’t know too many parents who have children with cochlear implants who are failing. . . . I think that’s the problem. It’s not

having someone with the same situation that's [saying], 'I totally understand where you're coming from.'" Jennifer saw her situation as unique, which contributed to her sense of isolation. Her child's lack of progress with language and communication development continued for more than two years. This prolonged period of time deepened her feelings of isolation in terms of her perceptions of others not understanding and her feelings of being alone:

I feel like I'm a one-man fiddle that's playing the same tune over and over and over and over again. . . . People are like, "Yeah, yeah, we've heard it before. Your child's got a hearing loss." Even amongst the family it's like, "Yeah, we know. Can you say something else other than she's struggling?" They get a little bit tired of it. [As a result] I kind of put my own feelings a little bit on the back burner because I feel like I don't have a whole lot of people to talk to about it.

According to McGuire et al. (2004), mothers often equate a lack of support from others with a lack of understanding which can increase their sense of isolation.

In the following interview excerpt Michelle talked about her husband's role in their daughter's rehabilitation and how it affected her. She seemed to be struggling with seeing her husband as a support for her and "a good father." Michelle's husband had offered some emotional support by attending appointments and by "being there"; however, Michelle still felt that she carried the majority of the responsibility for their child's well-being. She also realized that she was alone with the responsibility of ensuring that the work was done so that her child could be successful in using the CI:

My husband works all the time, and really, I don't know—if I wasn't here, what would happen to her, quite honestly? I mean, he's a good dad, but as far as things go, he always comes to all of her appointments in Vancouver and he tries to attend some of her speech sessions if he can. He always goes to anything like IEP [Individual Education Plan]; he's always there. But as far as the day-to-day, you know, going to speech therapy, it's usually me; and doing most of the work with her, usually me. So it's kind of like if I'm not up on everything, she would suffer, right?

Some of the mothers also discussed other people's unsupportive behaviours and lack of acceptance. Jennifer charged that her family's reactions to the diagnosis added to her difficulties and contributed to her feelings of isolation:

I had a lot of emotions all sort of crammed into me, and it was compounded by the fact that when I went to tell my family, they all denied it. I think every single one of my family members said, "No, we would have seen it. No. No. She can't be deaf. They're wrong." Nobody believed me; . . . [it] was really hard. . . . It made it even more maddening because you don't want the news to be true.

Rather than receiving support from her family members, Jennifer expended energy to support them.

Both Michelle and Jennifer described other experiences of unsupportive behaviour and lack of family members' acceptance of the child's differences as "really hard." Jennifer noted that some of her family members had refused to adapt to her daughter's communication needs: "They refused to learn sign language. . . . [They said,] 'We're too old for signing. . . . You're going to have to find some way to get her to talk.'" Jennifer interpreted their refusal to learn an alternate way of communicating with her daughter as a lack of acceptance of her daughter, which added to her isolation. A perceived lack of acceptance and family members' unsupportive attitudes contribute to mothers' feelings of isolation (Nelson, 2002).

Michelle believed that her family did not understand or support her and her husband's needs to both be present during their daughter's surgery:

[My husband's father and business partner] couldn't understand why [my husband] had to come with us for the surgery: "Why do you both have to go?" He didn't say anything to us, but he said everything to other people [complained about the husband leaving for the surgery].

The mothers also described professionals' unsupportive attitudes and behaviours, which contributed to their feelings of isolation. Mothers of children with cochlear implants are involved with a wide range of professionals, including physicians, audiologists, speech therapists, teachers of the deaf, and regular classroom teachers; many times the mothers perceived these professionals as unsupportive. For example, Jennifer talked about the moments after she received the initial diagnosis of deafness from the audiologist:

You're kind of in a muddle, you don't know what they're saying, . . . and I remember her kind of saying, "My next appointment is here" within two minutes of her saying to me— . . . We didn't go to another room, nothing. She just said, "Okay, well, I've got to go now."

The audiologist was insensitive to Jennifer's feelings and to what Jennifer might have been experiencing after receiving such devastating news. By not acknowledging Jennifer's shock at having just received potentially life-altering news about her daughter, the audiologist invalidated her feelings.

Sara talked about her experience of being judged and devalued during an IEP meeting with her child's teachers:

I get to these meetings, and they're talking about language and contents and grammar and this and that, and you're lost because you don't know the lingo. And then you think that they're judging your child, and you just feel yourself going lower and lower. There have been a few IEP meetings I came home from and ended up bawling. I'm a failure because [my] kid's not learning. You get caught up in it.

This experience demonstrates that professionals can cause mothers to feel belittled, excluded, and invisible when they use complex professional terms and concepts. She interpreted the teacher's evaluation of her child's progress or lack of progress as judging the child. In turn, she assumed the judgment herself as though the teachers were telling

her that she was a bad mother. The attitudes and behaviours of the teachers as Sara perceived them contributed to her feeling unsupported and ultimately alone.

Jennifer also experienced difficulties with being devalued by her child's teacher. When her child began to struggle in school, Jennifer met with the teacher to find out what she could do to help her daughter: "Unfortunately, I have a teacher who's like, 'Stop worrying so much about it. What's the big deal? She's in Grade 2. Maybe your fretting is the problem.'" The lack of regard for the mother's worry and concern for her child not only ignored the mother's concerns, but was also blaming and disrespectful of her.

Jennifer felt unsupported when she tried to find information and help when her daughter was initially diagnosed. She discovered that two of the three local centres were closing for the summer, which contributed to feelings of angst and despair:

I need help right now. I'm not sleeping. I am not eating. I am sick to my stomach. I have a million questions. . . . I remember being so irritated: . . . Why is it that my child is diagnosed right at the time that you guys are shutting down? What kind of stupid system is this? People are being diagnosed all year round; why would you shut down? . . . I was so mad that they were shutting. I thought it was the stupidest, most ridiculous system I had ever heard of.

Jennifer's needs, as she saw them, had not been met. When professionals work with mothers of children with disabilities, it is imperative that they make an effort to understand the mother's needs and desires as she sees and identifies them rather than as what the professional believes they should be (Most & Zaidman-Zait, 2001).

Physical or environmental factors are other potential causes of feelings of isolation (Nelson, 2002). Two of the mothers spoke of feeling isolated as a result of living in smaller communities. Specifically, they talked about not having people in similar situations with whom they could connect. Michelle said, "There's not much

support here. . . . There's one other family with a CI, but we didn't really connect. . . . We felt like we were the only ones."

Sara also felt alone and without support as a result of living in a smaller area:

"You just don't have the support you do in a bigger area." She also talked about trying to connect with others:

You put your name out there [in the CI community throughout BC] for contacts, and there's the odd person I talked to on the phone, but there was no meetings face to face. . . . I just wished that I would have somebody to talk with. You just do the best you can.

Not connecting with others who were experiencing similar things was difficult for Sara:

"You need to share; you need to have somebody that's gone through it to understand and empathize a bit with you so you can get it and move on." Sharing experiences with others in similar situations helps to validate feelings, present strategies for coping, and may ease the feeling of isolation (Luterman, 2003; Most & Zaidman-Zait, 2001).

Feelings of isolation were evident in many of the mothers' experiences.

Underlying many of the stories were their feelings that they were alone and that no one understood what they were facing. The mothers also reported that other people's attitudes and behaviours made them feel that they were being set apart because their children were not being accepted. They also talked about feeling unsupported.

Summary

Feelings of uncertainty and isolation were prevalent in many of the mother's experiences. For each of the mothers a change had taken place when she learned of her child's deafness. Change may be seen as intrinsically unpredictable, which can evoke feelings of uncertainty. After a child receives a diagnosis of deafness, mothers often feel uncertain about how to be a mother to a child who is deaf. They are unsure of their

child's future and worry about whether others will accept the child. CI provides an option for some of these children and their families (Luterman, 2003); however, the CI process itself is also full of uncertainty. The mothers in this study had feelings of uncertainty during the approval process and later during the actual CI surgery. The unpredictability of how their child would respond when the CI is initially activated evoked further feelings of uncertainty for these mothers. Uncertainty continued through to the challenge of living with a child with a CI who is actively undergoing rehabilitation to the unpredictable nature of the child's future.

Many of the mother's stories also communicated feelings of isolation. The mothers felt that they were alone in coping with a variety of situations and that others did not understand. Specifically, the mothers perceived that some of the other family members, friends, and professionals with whom they associated did not understand what it was like to be a mother of a child with a CI. The mothers also believed that others often did not recognize or understand the work and effort that it takes to help a child with an implant learn to hear and begin oral language. The mothers' perception that others did not accept their child's uniqueness and special needs also evoked feelings of isolation. They also described the isolation of feeling unsupported.

Exploring the mothers' feelings of uncertainty and isolation has revealed the complexity and intensity involved in being a mother of a child who has undergone the CI process. Personal crises are often life changing, and events such as these can make people feel that they have lost their sense of balance from within (McGuire et al., 2004; Williams, 1999). All of the mothers in this study experienced a loss of balance within their lives in relation to the variety and intensity of their experiences from their child's diagnosis through to the ongoing rehabilitation.

Theme 3: Moving On

Moving on was the third theme that emerged from the mothers' stories. The mothers seemed to move on or move forward as demonstrated by the change in their actions and perceptions of their experience of having a deaf child with a CI.

Positive Expressions

At times the mothers spoke about their experiences in positive ways. Their stories revealed that their positive outlook helped to change the way that they viewed their experiences and helped them to move on. They started to regain a sense of balance and well-being, and in this section I discuss how their shift in thinking toward a more positive outlook contributed to their new appreciation for life.

According to Larson (1998), people generally tend to focus on the positive rather than the negative aspects of life. Negative events can evoke powerful emotions. People often experience both negative and positive affects during personally significant, enduring stress (Folkman & Tedlie Moskowitz, 2000). Folkman and Tedlie Moskowitz maintained that a positive affect serves important adaptational functions in the coping process and can be generated and sustained with three kinds of coping strategies: positive reappraisal; goal-directed, problem-focused coping; and infusion of ordinary events with positive meaning.

When the mothers of chronically ill children in Gibson's (1995) study accepted the reality of their situation, they reorganized or reconstructed the meaning of life. The mothers employed a positive style of thinking that helped them to see their situation in a more optimistic way and eventually make a conscious decision to move forward.

For the mothers in this study, learning that their child was deaf was a significant, stressful event (Seabrook & Rodda, 1991). To reconcile the impact of learning of the

disability, the mothers gradually revised and reconstructed the meaning of the event (Larson, 1998). By reframing the situation in a more positive light, they were able to see the situation more positively and in time were able to shift their attitude from despair to optimism (Folkman & Tedlie Moskowitz, 2000; Larson, 1998). Michelle commented that she was learning to accept the reality of having a child who was deaf and was ready to move on: “Hey, let’s get on with life! It is what it is, can’t change it, so—”

Sara seemed to accept her new reality in part as though it was her destiny: “Everything in life happens for a reason.” Later, she added, “You’re put on a path because you can handle it.” Nelson (2002) described accepting one’s fate and moving on a process of “playing the hand you’re dealt” (p. 522).

Taanila, Syrjala, Kokkonen, and Jarvelin (2002) suggested that mothers who have an optimistic attitude toward their child’s future have an easier time accepting the situation. Some scholars have found that positive and optimistic attitudes can bolster subjective well-being (Folkman & Tedlie Moskowitz, 2000; Larson, 1998). A positive outlook can also help to regain a sense of balance and feeling more balanced within often helps to create a sense of well-being (McGuire et al., 2004).

In reflecting on her experiences, it seems that Colleen had reframed them in a more positive way that enabled her to understand how she had changed personally: “I wouldn’t trade anything I’ve gone through. It’s made me a stronger person; it’s made me a more passionate person.”

Jennifer commented on her experiences in general that “it’s been an interesting journey with its highs and lows.” This suggests that she perceived both positive and negative aspects. Like Colleen, Jennifer also felt that her experiences had made her a stronger person.

Sara talked about some of the good things that had resulted from having deaf children:

There are benefits on some level to having deaf children, because when you take off their gear, you can get away with a lot of stuff! I can still crank the tunes and party on, or I can still watch my movie in surround-sound with everything blasting.

She had potentially reframed her perception of her situation in a more positive light, which helped her to see the upside of her situation.

Gibson (1995) found that when mothers of children with disabilities think positively about their life in general, they can often develop an appreciation for the inherent goodness of their situations. The mothers in this current study also spoke about seeing things in their lives differently and developing a new appreciation for them. Colleen said, “She has opened our eyes to so much. . . . It’s made me more aware of things that are out there: the wind blowing, the sound of a dog barking. . . . She has taught us to appreciate life more.”

Michelle compared her experience of her child’s learning to talk after the CI surgery with that of mothers of hearing children: “I think as a parent of a kid like that [deaf with a CI], when they talk, you appreciate it.”

A positive outlook helped to change the way that the mothers saw their experiences and helped them to move on; it also motivated them in their efforts to manage their changed lives.

Taking Action

Taking action was an additional component of the theme of moving on that emerged from the mothers’ stories. It included various ways that the mothers managed their new reality of having a deaf child who was undergoing a CI (Taanila et al., 2002):

information gathering, deciding to implant, looking for and finding support, navigating the system, and helping others (Folkman & Tedlie Moskowitz, 2000). Similar to developing a positive attitude, taking action had many benefits for the mothers, such as helping them to maintain and restore their balance within. Pursuing these activities also helped them to feel some sense of control over their situations (Folkman & Tedlie Moskowitz, 2000; Green, 2004; Taanila et al., 2002).

The mothers initially took action after the diagnosis by gathering information. The quest for information is a typical response to unknown circumstances to understand a situation (Gibson, 1995). This activity serves a dual purpose: first, to reduce stress; and second, to obtain information that will most likely help with decision making (Most & Zaidman-Zait, 2001).

Michelle talked about spending three days on the computer and telephone after her child was diagnosed, “trying to find out everything that I could.” Sara also collected a massive amount of information:

In the beginning I think I kind of chewed it all off. . . . You get the books, you download every single thing you possibly can, print off information. That whole filing cabinet’s probably all deaf and hard-of-hearing books, photocopies, different signs.

Jennifer remembered the initial days after learning of her child’s deafness as particularly difficult: “At that point I wasn’t eating properly. I wasn’t sleeping because I was up all night doing research on what does *hearing loss* mean, what does *deaf* mean?” She had received three pamphlets from the audiologist, one for each of the centres in the community that worked with deaf children. Her quest for information continued with phoning and visiting each of the centres: “That’s how I’m going to get a handle on this, through education.” Gibson (1995) reported that even if the information is distressing,

mothers can receive a degree of comfort from knowing more about what is happening. Seabrook and Rodda (1991) maintained that information-gathering activities are part of the denial stage of the grieving process, a normal defence mechanism that allows mothers to retreat from painful feelings.

Michelle also recalled her initial information-gathering experiences:

When she got diagnosed, it was just like a big push to get as much information as you can get, and—I don't know—if it wasn't for that, if it would have affected me more. Like, I kind of have a purpose; I'm out there; I'm trying to get information on how we're going to do this.

Having something to do, an activity to keep her busy and occupied, seemed to help Michelle. Although her efforts were directed at acquiring knowledge to understand and deal with her new reality, she also gained a sense of control from these efforts (Folkman & Tedlie Moskowitz, 2000).

Nevertheless, Colleen found this period of information gathering difficult because of the vast amount of information that she had to sort through and understand so that she could decide what to do:

The first part of it was so overwhelming for me because of all the paperwork. . . . They gave us a whole bunch of pamphlets about the cochlear implant—what was out there for a deaf child, the schools. [It was] like a tidal wave of information and choices, and that's why we interviewed the three places before we continued on with the [CI] procedure.

Making the decision that their children would receive an implant was another way that the mothers took action. At some point during their information-gathering activities, each of the mothers learned about CI as a possible option for their deaf children. The process of making a decision to implant is typically very difficult for parents and often the hardest decision of their lives (Luterman, 2003; Most & Zaidman-Zait, 2001).

Archbold (2001) described it as a complex and stressful process that involves a combination of previous experience, knowledge, and information, as well as tension between a mother's hopes/expectations and doubts/cautions.

According to Zaidman-Zait and Most (2005), the mother's stage in the grieving process and her methods of coping may influence her decision to implant, as difficult as it may have been. Whatever the factors that influence her decision, it appears that having options and the ability to take action by making a decision potentially help the mother (Gibson, 1995). I discuss the struggles and feelings of grief that the mothers shared in their stories about their decision making in this section to enable a deeper understanding of their experiences.

Jennifer appeared to be confused and uncertain when she was considering a CI for her daughter: "Every day would be yes, no, maybe; . . . it would be all over the place. . . . We were literally on the fence." She had a particularly difficult time making this decision: "My biggest struggle as a mother was that she had come to me, she had come out of my womb with this problem with her ears. Was this her destiny? Was this the way that she was supposed to be?" It was, in part, a "spiritual battle" for her: "I was angry, and I felt like my prayers were kind of bouncing off the ceiling. . . . I was confused: Is she meant to be like this? This is how she's come to me." She debated the issue from other perspectives as well:

From a medical point of view, obviously that's absurd. . . . If you're missing a limb, you get a prosthetic device; or if your heart is not working, you repair it. But from my simple point of view, maybe this is the way she's supposed to be.

Eventually, Jennifer decided to offer her child a choice on the CI, and she explained her reasons through an analogy:

You cannot pick between chocolate and vanilla [ice cream] if you never get to taste the vanilla. . . . She needs to be able to taste what hearing sounds like so that she can choose to take it off. . . . She can always choose to be deaf again, but she can never choose to hear once that window of opportunity is gone.

The decision-making process was also difficult for Sara, who spoke of the responsibility of making the decision for her son:

It was a hard decision, it was really hard, and I think as a mom you feel responsible for everything. I need to provide the best learning opportunities that I can for you, and communication's it for everything that you're going to go through in life. It just didn't make sense to me not to arm a kid with everything possible, and then he can decide later whether he likes it or not. . . . The bottom line, I came to the decision that you need to hear in order to get through life as best as you can.

This narrative illustrates the enormous feeling of responsibility that Sara felt while she was making this decision. Mothers of children with disabilities often have a heightened sense of responsibility for their children (McGuire et al., 2004). This is influenced by Western cultural views that parents, and particularly mothers, are expected to take on a great deal of responsibility and are, at least to some extent, held accountable for their child's disability (Milliken & Rodney, 2003).

Considerations of the seriousness of the surgical procedure and expectations of parental commitment added complexity to the decision-making process. CI is an irreversible, invasive procedure that requires an enormous commitment on the part of the family in both personal and financial terms (Most & Zaidman-Zait, 2001; Russell & Coffin, 1999). Colleen needed time to learn and understand everything about the CI even though her husband was ready to proceed immediately:

I didn't know anything about it, and . . . it's invasive, and it's in the head and brain. . . . After the initial guilt was over, we decided that it was the best thing. Why not? It was the opportunity to be able to . . . have her hearing as normal as possible.

For Michelle, the decision to have her daughter implanted was “a no brainer”:

I’m not sure where we came up with the idea that this implant was the be-all and end-all, but somewhere. . . . [So] as soon as I figured out they couldn’t fix [her hearing], I started actually hoping that her hearing would be bad enough to get an implant.

Michelle also talked about past experiences with a family member who could not communicate verbally because of health problems: “I saw how it had affected him. He couldn’t communicate with anybody; it totally changed his life, and people were afraid of him. . . . I didn’t want that for my daughter.” These past experiences obviously had a great impact on her and ultimately influenced her decision to implant.

Looking for and finding support was another way that the mothers took action. They offered a number of examples in which they actively searched for help and support. It is interesting that most of the mothers focused on *not* being able to find support (see theme 2 on feelings of uncertainty and isolation). They talked about finding support from their husbands or partners, other family members, professionals, and organizations associated with hearing loss and CI and described feeling supported when they were able to find people who helped to meet their children’s needs, including educators, childcare providers, and some of the people from the CI team; specifically, the surgeon and audiologist.

A mother’s need for support can change between the initial diagnosis of deafness and the lengthy implantation process (Most & Zaidman-Zait, 2001). Where we find support and when we feel supported are different for everyone (Seabrook & Rodda, 1991). Finding support can be beneficial for mothers in many ways. According to Brett (2004), by asking for and accepting support, mothers potentially put themselves in control. Luterman (2003) maintained that what people in pain need most is to be listened

to and to have their feelings validated. In Nelson's (2002) study, "mothers expressed clearly that an important quality of supportive health professionals was that they listened" (p. 528). Looking for and finding people who support their needs in some way is a strategy that mothers use to move on (Folkman & Tedlie Moskowitz, 2000; Taanila et al., 2002).

Family is often a support system, and for a mother, it is typically her husband. Thus his reactions to events and how he participates can have a major influence on the mother's experience. One mother recalled her husband's reaction to learning about their child's new hearing-loss diagnosis: "I walked in the door and handed him the audiogram. He said, 'She's deaf. . . . It's going to be okay. We'll deal with this, but I don't want to talk about it right now.'" When I asked her how she felt about his reaction, she said, "One part [of me] felt I could kind of sigh a bit of relief. . . . If he's not worried, I shouldn't be worried. It kind of calmed me down."

Jennifer talked about the ways in which her husband supported her:

I get overwhelmed sometimes. . . . Every once in while I have a bad day where I'm like, "For once I just need to be listened to. I just need a little space." And he's really good. He'll be like, "Okay, sure. Hey, guys, let's go get a pizza. Mom just needs a break."

Sara had some "down time" when her children went to their father's house. She was supported by the man in her current relationship, and it felt so different for her:

He just walked through my front door ready and willing to accept my family. . . . He's the first one who's actually come to school meetings with me; he's come to all the audiology appointments with me. . . . You don't realize how much you're doing until someone else comes along.

Other family members are important sources of support for mothers (Seabrook & Rodda, 1991). It is interesting that only one mother discussed feeling supported by other

family members. Michelle's mother lived in close proximity and frequently helped out and supported her. She also felt supported by something that her grandmother had said: "I don't care if we have to learn sign language; we'll all go and we'll learn, and we'll do whatever we have to do....They've always been fine with it." How others accept or do not accept the differences in a child with a disability can have an impact on the mother (Nelson, 2002).

The mothers also searched for support from professionals and organizations associated with hearing loss and CI. Jennifer had a difficult time finding an organization that would help her because two of the three resource centers in the area were closing for the summer. However, she eventually connected with someone, and it changed her experience considerably. When Jennifer telephoned the third resource centre, the woman came right over: "It was just amazing. I'm like, 'Who are you?' I really felt like she was this angel that just kind of dropped out of heaven." Jennifer described this woman as "just like this major support," "a fountain of knowledge," and "totally nonthreatening and respectful"; and she "sort of bridged that gap between, . . . the knowledge gap."

Often the support that the mothers received helped them to shift their perspective toward a more positive outlook. Jennifer commented that the woman from the resource centre helped her to put things into perspective: "[The woman said,] 'Your emotions and feelings are very important, but your child is not dying; she just can't hear. . . . It's not the end of the world for your daughter.' It just gave me a sense of optimism." Jennifer related what this woman said that helped her: "She's like, 'This is about you. You just talk, and I'm here for you. You just say what you need.' . . . I just had the feeling that she would have done anything and everything to get me what I needed."

Zaidman-Zait and Most (2005) suggested that CI requires that professionals inform, guide, support, and collaborate with parents on a continual basis and that establishing a collaborative relationship between parents and professionals is especially challenging with CI because of the range of the professionals involved in the multistaged process and the changing needs of the parents. They reported that good relationships are important to aid in both parental coping and involvement in the child's therapy. It is interesting that only one of the mothers (Colleen) talked about feeling supported by the professionals on the CI team: "We are so lucky to have the team we do. . . . [The audiologist] was such an awesome support, and he still is. . . . [Dr. R.] was just so awesome with her at the initial meeting and everything."

Jennifer described the support of the surgeon, but for reasons more closely related to feeling respected: "[Dr. R], the surgeon, I just love him to bits. He was always the most supportive [of the CI team]. . . . He was the most respectful of our choices." The surgeon is often the professional whom most parents prefer to deliver information and services (Most & Zaidman-Zait, 2001).

Two mothers talked about finding support from peers. Support groups can be of immense value and peer support groups are typically safe places where mothers can share their experiences with each other (Luterman, 2003). Giving and receiving support can help them to gain a real sense of being understood and connected (Gibson, 1995). Sharing experiences with others in similar situations helps to validate feelings, present strategies for coping, and may ease the feeling of isolation (Luterman, 2003; Most & Zaidman-Zait, 2001). Colleen talked about her experience of participating in a support group: "Everybody can talk about issues that parents that have already been there [face], and then

eventually you become the parent that's there, and the new parents come in and you can help them out, and it's just great."

Michelle also participated in a support group when she visited a special clinic in the United States: "They called it 'Blubber Hour.' . . . It was where everyone would talk about their situation. Everybody goes through the same thing, but we were all in the room saying, 'Nobody else gets it except for parents sitting in the room.'" Michelle also received support in the form of private counselling:

I went to therapy because they offered it—free therapy. Don't know how I found out about that, but I figured, hey, sign me up. So I would go every week, and I did that for about eight months, and that was basically how to reorganize your life and put everybody else behind what's really important, and that was when I stopped working so much.

The mothers seemed to feel supported when they found people who could meet their child's needs. Children who are deaf with CI require varied support, including in language and communication development as well as emotional and psychosocial developmental (Most & Zaidman-Zait, 2001; Preisler et al., 2002).

Sara felt a sense of support from the people who worked with her children:

I was running into people that just happened to have these skills that I needed for my kids, and it was really cool. Without the support people that my kids had, they would not be where they are today— . . . educators, their daycare people. They just can't say enough about what good kids they are. So I know I'm doing something right.

Colleen also seemed to feel supported when educators and daycare people met her daughter's needs:

Her daycare lady used to be an early-education teacher, and she does sign with all her kids—the hearing ones. She teaches them all sign, and [my child] was her first child with a cochlear implant, and oh my God! you'd think she's her child. . . . Her daycare lady is just unbelievable, and M, her supportive childcare gal. . . . You can actually feel when you're with them that they care about your child.

Mothers of children with disabilities are often apprehensive about leaving their children with others because of the concern that others will not be able to meet their child's needs (McGuire et al., 2004; Nelson, 2002). Thus, when Colleen saw her child being included and well cared for, she felt supported.

Another way that the mothers took action to manage their new reality and to move on was by working with and in the bureaucracy of the organizations associated with CI. Once they had made the decision to implant, their focus and energy were typically redirected towards navigating through the bureaucracy of the organizations associated with CI. This included the approval process for CI, the surgery, and negotiation with associated organizations. The mothers' ability to move on seemed to depend on how easily or quickly they moved through the different CI processes. Important in the discussion of the mothers' capability of moving on by taking action through negotiating the bureaucratic systems were the barriers that they encountered along the way. These have been included in the mothers' accounts to demonstrate that moving on through taking action often entails effort and struggle.

Sara talked about her experiences during the approval process: "Well, there's a huge criteria, . . . like a page and a half. . . . It was a lot of appointments and going back and forth to different doctors." Sara's son eventually met the lengthy list of criteria without any trouble. The many trips back and forth from the small community where they lived to the larger centre where the only CI program in BC was located were difficult; they were taxing both emotionally and physically for this mother and her child.

Both Jennifer and Michelle had to overcome the same obstacle before they were able to move on. Each child had been approved for an implant; however, there was a two-to three-year wait list for the surgery. Jennifer said:

There were only six [surgeries] being funded at the time, and there was thirty [names] on the waiting list. . . . We were not going to wait. We will go to Seattle and pay cash. I will do whatever it takes. I'll sell my house. I'll sell my van. I'll do whatever it takes to get this child a cochlear implant if we need to. I'm not going to sit on the waiting list for a year.

Her desire for her child to have an implant was so strong and the resistance from the CI program was so great that she fought with every means possible:

This is what we want, and we want it now. We don't want to have to wait, and we will go elsewhere. We will go public about it. If you say no to us, we will go elsewhere, and we will call the media, because I'm not going to be denied an implant because my child signs. That's just wrong!" I felt it was wrong that they made me sign a sheet saying "You cannot sign [after the surgery]". That is just ridiculous!

Jennifer's actions appear to have been fuelled by frustration, anxiety, and fear of the failure to obtain what she felt would help her daughter. Mothers often experience feelings of frustration when healthcare professionals minimize, negate, or ignore their concerns (Gibson, 1995). Once everything was arranged and her daughter received a date for surgery, Jennifer was able to move on.

Michelle's child received approval quickly for implantation; however, the problems began when she discovered the long wait list for surgery in BC: "We thought, We can't wait four years! Her whole speech function would be gone! . . . Lots of sleepless nights. . . . And that was my biggest concern about getting the implant." Like Jennifer, Michelle considered selling their assets to pay for the procedure in the United States. Fortunately, the CI program in Vancouver arranged for her child to be assessed in Toronto with the hope that the surgery would be done there. However, they had to go back to the beginning of the approval process in Toronto:

We had to go through the whole process of getting it approved in Toronto because they wouldn't take Vancouver's word that she was eligible; she had to be eligible

under their hospital rules. So when we went there, we didn't know if she could get implants or not. We had about a week and a half of testing before we knew if they would implant, which was probably the most stressful. Even the diagnosis wasn't as stressful as what happened in Toronto. . . . I just wanted her to fail [the tests] so bad so that she could get the implant, and we were so desperate. I was just sick; I don't think I've ever been so stressed in my entire life.

Michelle's ability to move on was delayed until she received approval for the surgery.

Colleen talked about her experiences during the approval process. Her child had also been added to a long wait list, but everything changed dramatically: "We were going to have to go to Toronto; then the government put in 1.5 million dollars more, and now the list [of children who were to receive an implant] was up to 12, and [my daughter] was on it."

The mothers also took action by navigating the systems of the organizations associated with hearing loss and CI. For Jennifer, proceeding through the bureaucracy was particularly difficult: "We really had to fight for what we wanted." Once Jennifer decided to implant, she faced two roadblocks, first, from the resource centre where she was receiving support; and second, from the CI program. The resource centre held strong philosophical beliefs about deaf culture and the use of sign language. Once the option for CI was presented, the centre prepared to withdraw its services, and the possibility of losing her main source of support created great distress for Jennifer: "I just love this woman so much, and I'm like, 'I can't leave you, but I want to look at this option for my daughter.'" Because Jennifer still planned to sign language after the implant, the centre agreed to continue to support her, which made her family "the first family to ever have a cochlear implant and stay with [this resource centre]."

Although Jennifer's conviction "to keep up deaf culture, to sign full time and learn to speak full time" helped her to retain the resource centre as a support, it ultimately

“caused a big problem” with the CI team. The fight for what the family wanted for their child resumed as they met with the people from the CI program. The confrontation in the meeting was obvious: “We sat around a big table and had to sort of plead our case. And I remember there was like five of them sitting there and the two of us.” After much discussion, the CI was approved. This mother was finally able to move on after taking action by negotiating with the resource centre and the CI team.

Helping others in similar situations was another way that the mothers took action. They talked about ways that they helped other parents in similar situations. Gibson (1995) and McGuire et al. (2004) suggested that helping others in like circumstances can be fulfilling and may facilitate feelings of well-being for mothers who have children with a disability. Schwartz and Sendor (1999) maintained that helping others can be beneficial to the helper in many ways, including enhancing feelings of personal control, self-worth, and self-confidence. Gibson reported that mothers eventually become aware of their strengths and abilities and develop confidence in their knowledge of the situation. Once they are aware of these changes, they often take charge of the situation in a proactive manner and develop a sense of personal power. Then, according to Gibson, some of this energy may be redirected toward other activities such as helping others.

Jennifer talked about what she had done to help others and how it had helped her:

I go around talking about hearing loss and help others that are trying to get implants. . . . It does help speaking to others that are newbies—you know, people that have just been diagnosed. . . . I kind of focus on how to help others to kind of get me through it.

It seems that developing a certain level of confidence in her knowledge and ability to deal with the situation aided Jennifer in sharing her experiences and helping others:

A lot of people kind of will compliment me on it, saying, “Wow, you guys have been through so much! Your courage!” And that has really taught me a lot. “And I just love the way you speak! . . . You really are an inspiration to me.” . . . [Hearing] that kind of helps me.

Having her experiences endorsed was valuable to Jennifer in many ways. According to Luterman (2003), sharing experiences with others in similar situations helps to validate feelings. For Jennifer, taking action by helping others facilitated her moving on.

Michelle discussed her hope of helping others: “I feel like I want to make something good of it or somehow improve people’s experiences that come behind me. I don’t really know how I’m going to do that, but—” She too felt a desire to help by easing the path for others who were just embarking on the journey that she was still in the midst of making. Michelle’s comment also suggests that helping others may have been a way for the mothers to shift their perspectives toward the positive and see the experience as worthwhile.

Both Colleen and Sara reported that other parents had phoned them and met with them. Colleen said, “[It’s] not a problem. There’s a family now that we’re going to meet.” Sara added:

But it’s amazing. People don’t want to impose on you, and I think it’s probably the one thing that you do want to share. . . . You need to share; you need to have somebody that’s gone through it to understand and empathize a bit with you so you can get it and move on.

Her comment reiterates the importance of sharing experiences with others in similar situations (Luterman, 2003).

Another way that two of the mothers helped others was to work with the television media. Michelle did “a couple of little TV things,” whereas, at the suggestion of her audiologist, Jennifer agreed to have her daughter’s turn-on session filmed:

[My daughter's] audiologist said, . . . "I think her turn-on will be really successful. I think it would be really nice for people in the industry to see how well cochlear implants can go." And so we agreed to that, and [the TV crew] was on location live when she got turned on, and it was picked up by the national news, and it was aired for two days. . . . People all over the country saw her, and people were so encouraged by her story.

Helping others enhanced participants' feelings of personal control, self-worth, and self-confidence (Schwartz & Sendor, 1999).

Summary

The theme of moving on illustrates that the mothers moved on or moved forward with their experience of being mothers of a child with a cochlear implant. The mothers provided rich descriptions of actions taken to help manage their new realities, and these actions helped them to restore and maintain a balance within and gave them a sense of control.

Going through the process of accepting the new situation with their children helped these mothers to find new meaning in their lives. They became aware of their strengths and abilities and developed confidence in themselves, which helped to mobilize them to gather information, decide to implant, find support, navigate the system, and help others. The mothers showed tremendous strength in their ability to persevere through numerous obstacles and barriers and to move on. They moved beyond their old ways of thinking and being and found new ways of living.

CHAPTER FIVE: DISCUSSION

The focus of this research study was to explore the experiences of mothers whose children have gone through the CI process. Using a Narrative Inquiry approach I explored the experiences of four mothers as expressed in and by their stories. I conducted a thematic analysis using a seven-phase process based on an adaptation of Fraser's (2004) work. Three themes emerged from the mother's stories: struggling with new realities, feelings of uncertainty and isolation, and moving on. Many of the experiences included in the three themes occurred simultaneously. For example, in struggling with their new realities, the mothers were often also experiencing feelings of uncertainty, while at the same time taking actions that would ultimately help them to move on.

In this chapter I discuss the importance of the study as well as understandings of the findings, the limitations, implications for practice, and directions for future research.

Significance of the Study

Cochlear implantation is an increasingly common pediatric rehabilitation option for children with sensory-neural deafness (Zaidman-Zait, 2007). It has been suggested that parents are essential to the success of children using this technology (Nikolopoulos et al., 2001; Russell & Coffin, 1999). Although CI techniques and processes are well documented there are few studies available that examine the experiences of parents who have a child undergoing the CI process and few of those use qualitative perspectives.

The process of having a child undergo CI can be difficult and stressful for parents. Mothers often carry the brunt of this because they are the most likely parent to care for, support, and advocate for the child throughout the CI experience. Exploring mothers'

stories of the CI process helped to facilitate an understanding of their experiences. Using a Narrative Inquiry approach I was able to illuminate an in-depth understanding of the experiences of four mothers whose child had undergone a CI. The findings of this study add to the knowledge of paediatric CI and specifically to the experiences of mothers whose children have undergone the CI process. Having an in-depth understanding of mothers' experiences can inform and guide professionals' practice and enhance support and services.

Unique Contributions of This Study to CI Literature

Some of the findings from this study confirm previous research that focused on work related to mothers of children with disabilities. This study establishes a relationship to these findings or concepts, specifically in the context of mothers of children with CI. For instance, the mothers in this study struggled in ways comparable to those of the mothers in Nelson's (2002) metasynthesis of 12 studies on mothering other-than-normal children. "Negotiating a new kind of mothering" (p. 522) was one of the themes that Nelson reported in her findings. It encompasses the findings that the mothers experienced a large learning curve, developed and continually changed their relationship with the health care system, developed a new and different kind of relationship with the child and other family members, and became strongly aware of societal judgment of their children and themselves. The findings of this current study are similar to those of Nelson's research but are woven throughout the three themes in different ways.

Another example of the support of previous research for this current study's findings, although in a different context, is with regard to the phenomenon known as *cyclical grieving*, in which one reexperiences feelings of grief (Blaska, 1998). According to Blaska, these powerful emotions are often triggered by specific events, during times of

transition, or in a new developmental stage in the child's life. The mothers in this study described experiencing this phenomenon. For example, being reminded of their child's differences brought back feelings that they had experienced at the beginning when their child was first diagnosed. Past research on cyclical grieving (Blaska, 1998) and nonfinite loss (Bruce & Schultz, 2002) supported these findings. This current study adds to the work of Blaska and of Bruce and Schultz in that it ties the concept of reexperiencing grief to mothers of children who have undergone the CI process.

The findings in this study also support previous findings on some of the difficulties that mothers face during the process of learning that their child is deaf. For example, Luterman (2003) examined the feelings of parents who faced a diagnosis of deafness, including anger, guilt, and denial. Such feelings are associated with the sense of isolation and alienation that often comes with parenting a child who is deaf (Luterman, 2003). Seabrook and Rodda (1991) described the stages involved in the grieving process that parents experience when their child is diagnosed with deafness. The difference in the current study is that the mothers described having similar intense feelings at different times in their overall experience from the initial diagnosis of their child's deafness and throughout the CI process, and at times they still have them.

Moreover, the findings pertaining to some of the experiences of the mothers specific to the CI process itself are supported in the CI literature. For example, the struggle of parents faced with the decision to implant has been well documented (Luterman, 2003; Most & Zaidman-Zait, 2001; Zaidman-Zait, 2007). The anxiety and fear associated with CI surgery have also been reported in previous studies (Allegretti, 2003; Most & Zaidman-Zait; Russell & Coffin, 1999; Zaidman-Zait 2007), as have the stress and anxiety that parents feel during the initial activation and programming of the

device (Allegretti, 2003; Zaidman-Zait, 2007; Zaidman-Zait & Most, 2005). This current study pulls together much of the knowledge and understanding from past research on CI in a comprehensive way and encourages the reader to consider these ideas from the mothers' perspectives and within a vast array of experiences.

Overall, this study is an extensive exploration of mothers' experiences and has offered in-depth understandings of the phenomenon from the mothers' perspectives. Moreover, a comprehensive exploration into the three themes of struggling with new realities, feelings of uncertainty and isolation, and moving on enable us to understand the mothers' experiences in a particular way that is distinctive to this study.

Another unique aspect of this research compared to past studies is the multidimensional perspective that an NI approach brings. Considering mothers' experiences in terms of a three-dimensional inquiry space along temporal and personal-social dimensions as well as within place (Clandinin & Connelly, 2000) adds complexity and fluidity to the overall understanding. I believe that all of these different perspectives add considerably to the distinctiveness of the study and, in turn, to CI knowledge overall.

One final unique quality of this study is my perspective as the mother of a child who has undergone the CI process. I maintain that this emic or insider's perspective (Wicks & Whiteford, 2006) helped to create an atmosphere conducive to sharing and, in turn, encouraged deeper conversations to further enrich the data. According to Wicks and Whiteford, an emic perspective is crucial in understanding the meaning constructions of a specific phenomenon.

I believe that being an insider helped me to understand the depth of the mothers' experiences. Having experienced the CI process with our children, we shared a knowing or an understanding. Camaraderie or fellowship developed between us and seemed to

help the mothers feel understood on a deep level. During a follow-up conversation one of the participants stated, “You get it! You understand because you’ve been there!”

Personal Transformation

Many of their experiences had a significant impact on the mothers’ lives. A critical life event such as the diagnosis of a disability can create disorder, chaos, and uncertainty and often disrupts the order of one’s life (Neill, 2000; Wade, 1998). According to Neill, such events also lead to the possibility of inner growth and resolutions to a more harmonious state; when this occurs, the individual can be said to have gone through a personal transformation.

The findings of this study indicate that the mothers created new meaning in their lives through transcending the old ways of perceiving and being. They reframed their situations in a more positive light, and in time their attitude shifted from despair to optimism; they spoke of seeing things in their lives differently and developing a new appreciation for things. They began to manage their new reality of being mothers of deaf children who have undergone a CI by taking action such as seeking out information and finding support. They had moved beyond their old ways of thinking and being and had found new ways of living.

The association of the process of personal transformation with something that the mothers of children who had undergone CI were experiencing is unique to this study. However, the notion that these mothers potentially changed their perceptions by reconstructing the meaning of an event to develop a positive attitude and experience a transformative change within can be supported from the different perspectives of past studies (Folkman & Tedlie Moskowitz; 2000; Gibson, 1995; Larson, 1998; Zaidman-Zait, 2007). Folkman and Tedlie Moskowitz found that people generate and sustain

positive affect during times of chronic stress. Gibson explored the process of empowering mothers of chronically ill children and discovered that as the mothers adapted to their situations, they developed a sense of control and thus experienced a sense of empowerment from within. Larson found that mothers of children with a disability created a positive bias and regained a sense of control that fuelled their optimism. More specific to children with CI was Zaidman-Zait's (2007) study, which focused on parents' coping and revealed that, in time, parents altered their negative emotions and gained positive perspectives on deafness.

Other Contributions

This study is also significant for the potential benefit that the mothers received from participating in the research process. Narratives, or stories, not only help to give meaning to life, but are also a form of social and interpersonal action (Emden, 1998a; Lieblich et al., 1998; McLeod, 1997). Telling stories enables us to reflect on our life experiences to help us to better understand ourselves. Individuals often benefit from participating in research studies, particularly when they have the opportunity to tell their stories (Koch, 1998; Overcash, 2004).

Participating in this study gave voice to the mothers' experiences and fostered a sense of connectedness. The mothers had the opportunity to share their stories in their entirety; to decide where to start, what to include, and how deep to go. I believe that the research process helped them to feel that their experiences have been validated in some way simply by their being asked to share and given a space to tell their stories. The relational aspect of NI promoted a sense of connectedness between the mothers and me, a mother of a child with a CI, and, on a more abstract level, other mothers who have a child with a CI.

Finally, the mothers also benefited from participating in this research process because of their belief that they are helping others. Helping others is known to benefit the helpers, as previously discussed in chapter four (Gibson, 1995; McGuire et al., 2004; Schwartz & Sendor, 1999). Each mother reported her desire to help other mothers in similar situations and believed that participating in this research study was a way to help. I suggest that the mothers saw this research study as a legitimate way to do this and perhaps believed that it is a medium that has a potentially louder voice than their own standing.

Limitations of the Study

The aim of this study was to gain a better understanding of the experiences of mothers whose children have undergone the CI process. Even though in-depth stories of the experience were generated from the interviews the study is limited to the stories and experiences of four mothers.

The findings of this research are not generalizable in the traditional sense (Denzin, 1994). A social constructivist perspective maintains relativist ontology in that there are many or multiple realities (Morrow, 2007). However, multiple realities may have local generalizations and intersubjectivity (Denzin, 1994). For example commonalities were evident in the mothers' stories, implying similarities among many of the four mothers' experiences. Specifically, all of the mothers experienced a grief response to their child's diagnosis of deafness; suggesting they shared common or similar experiences. Despite these limitations, the experiences of these four mothers can shine light on multiple possibilities of experiences of other mothers within this specific context.

Implications for Practice

CI intervention programs are typically based on a family-centered approach which “purposes that professional provision of information, guidance, and support will empower parents to build a collaborative partnership in order to develop competence and involvement in their child’s education and development” (Most & Zaidman-Zait, 2001, p. 100). According to Most and Zaidman-Zait, although this approach appears to support children with CI and their families, the programs are usually designed on the basis of what the professionals think is important rather than on what the families determine is important for them. It is important that professionals allow the families, specifically mothers, to define their own specific needs rather than the professionals assume what their needs may be.

Professionals working with children who are undergoing CI typically focus their attention on the children. It is important, however, for them also to consider the children’s mothers as a significant element of the CI process. I believe that supporting the health and well-being of the mothers whose children are undergoing the CI process will ultimately help the mothers to provide for and support their children’s needs.

The following are specific recommendations for professionals who work with mothers who have children undergoing a CI:

1. Focus on mothers’ health and well-being. Help to identify, locate and put into place supports that facilitate the mothers to succeed in maintaining positive health, such as education, identification of barriers, and assistance with managing them.
2. Offer appropriate personal counselling to the mothers on an intermittent or ongoing basis as identified by the mothers themselves.

3. Assist mothers in establishing connections with others in similar situations (mothers of children with a cochlear implant), such as peer support groups. Work with mothers collaboratively who live far from others in similar situations to think of alternative ways of connecting peers, and if needed, of providing funding.

It is important that professionals who work with these families be educated to understand the struggles that these mothers face. In particular, they need to understand how to recognize mothers' emotional needs with regard to recurring grief. Professionals also need to determine effective ways to support communication and to develop skills so they may support the process of personal transformation within the mothers. Finally, it is incumbent upon the professionals who work with these families to advocate for policy changes relevant to meeting the needs of mothers such as obtaining funding for counselling or travel.

Implications for Future Research

As previously discussed, mothers are often the most likely parent to care for, support, and advocate for the child throughout the CI experience. In this study mothers were the main caregivers for their children during the process of CI; they did the work required to help their child learn language and communicate. More research is needed to understand strategies to assist mothers with this work while maintaining their health and well-being. Specifically, future research is needed to explore in depth what will help the mothers to move on (discussed in Chapter Four) including barriers that may hinder this process. The diversity of the inquiry may potentially be increased by involving: a) mothers from different cultural groups such as First Nations, b) younger mothers (under the age of 30 years), and c) mothers from a community located in northern BC.

Many professionals from a variety of disciplines work with these families during the multiple stages of the CI process. I believe it is important that these professionals gain a greater understanding of mothers' experiences so that they may learn ways to better support mothers. Future research studies conducted by professionals from these associated disciplines should take into consideration mothers' experiences, perspectives and needs.

It is important that future research involving mothers of children with CIs employ methodologies that utilize relational methods, such as focus groups. Such strategies will help mothers to connect with others in similar situations, potentially helping to break the isolation in addition to continuing to provide rich descriptive data for the research inquiry.

Research focussing on the experiences of fathers whose children have under gone the CI process is also missing from paediatric CI literature. Gaining fathers' perspectives will broaden the overall understanding of the phenomenon. Research that includes the perspective of all family members will further enhance our understanding of the impact of paediatric CI process.

REFERENCES

- Allegretti, C. M. (2003). The effects of a cochlear implant on the family of a hearing-impaired child. *Pediatric Nursing*, 28(6), 614-620.
- Archbold, S. (2001). Deciding to have a cochlear implant and subsequent after-care: Parental perspectives. *Deafness and Education International*, 8, 190-206.
- Archbold, S. M., Lutman, M. E., Gregory, S., O'Neill, C., & Nikolopoulos, T. P. (2002). Parents and their deaf child: Their perceptions three years after cochlear implantation. *Deafness and Education International*, 4(1), 12-40.
- Arvay, M. J. (1998). *Narratives of secondary traumatic stress: Stories of struggle and hope*. Unpublished doctoral dissertation, University of Victoria, Victoria, BC.
- Aston, M. L. (2002). Learning to be a normal mother: Empowerment and pedagogy in postpartum classes. *Public Health Nursing*, 19(4), 284-293.
- Avramidis, E., & Smith, B. (1999). An introduction to the major research paradigms and their methodological implications for special needs research. *Emotional and Behavioural Difficulties: A Peer Reviewed Journal*, 4(3), 27-36.
- Banister, E. (1999). Evolving reflexivity: Negotiating meaning of women's midlife experience. *Qualitative Inquiry*, 5(1), 3-23.
- Banister, E. (2002). Considerations for research ethics boards in evaluating qualitative studies: Lessons from an ethnographic study with adolescent females. *Annals RCPSC*, 35(8), 567-570.
- Barclay, L., Everitt, L., Rogan, F., Schmied, V., & Wyllie, A. (1997). Becoming a mother: An analysis of women's experience of early motherhood. *Journal of Advanced Nursing*, 25, 719-728.
- Bat-Chava, Y., & Martin, D. (2002). Sibling relationships of deaf children: The impact of child and family characteristics. *Rehabilitation Psychology*, 0090-5550, 47(1). Retrieved June 18, 2004, from the PsycARTICLES database.
- Bionic Ear Institute. (2006). *About the bionic ear: History*. Retrieved November 4, 2005, from <http://www.bionicear.org/bei/AboutHistory.html>
- Blaska, J. K. (1998). Cyclical grieving: Reoccurring emotions experienced by parents who have children with disabilities (Research Report Information Analyses). St. Cloud, MN: St. Cloud State University, Department of Child and Family Studies. (ERIC Document Reproduction Service No. ED419 349)
- Brett, J. (2004). The journey to accepting support: How parents of profoundly disabled children experience support in their lives. *Pediatric Nursing*, 16(8), 14-18.

- Bruce, E., & Schultz, C. (2002). Non-finite loss and challenges to communication between parents and professionals. *British Journal of Special Education*, 29(1), 9-13.
- Burger, T., Spahn, C., Richter, B., Eisselle, S., Lohle, E., & Bengel, J. (2005). Parents' distress: The initial phase of hearing aid and cochlear implant fitting. *American Annals of the Deaf*, 150(1), 5-10.
- Calien, R., & Hugo, R. (2002). Are parents of children with cochlear implants coping? *Health SA Gesondheid: Interdisciplinary Research Journal*, 7(2), 68-77.
- Callanan, V., & O'Connor, A. F. (1996). Cochlear implantation for children and adults [Electronic version]. *Lancet*, 347(8999), 412-414.
- Chase, S. E. (2003). Learning to listen: Narrative principles in a qualitative research methods course. In R. Josselson, A. Lieblich, & D. P. McAdams (Eds.), *Up close and personal: The teaching and learning of narrative research* (pp. 79-99). Washington, DC: American Psychological Association.
- Chase, S. E. (2005). Narrative inquiry: Multiple lenses, approaches, voices. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 651-680). Thousand Oaks, CA: Sage.
- Chute, P. M. (2003). Educational challenges for children with cochlear implants. *Topics in Language Disorders* 23(1), 57-67.
- Clandinin, J. D., & Connelly, M. F. (1994). Personal experience methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 413-427). Thousand Oaks, CA: Sage.
- Clandinin, J. D., & Connelly, M. F. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.
- Cohen, N. L. (2004). Cochlear implant candidacy and surgical considerations. *Audiology and Neuro-Otology*, 9(4), 197-202. Retrieved November 6, 2005, from http://www.childrenshearing.org/custom/research_articles.html#Pove
- Connelly, M. F., & Clandinin, J. D. (1990). Stories of experience and narrative inquiry. *Educational Researcher*, 19(5), 2-14.
- Corbin, J., & Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry*, 9(3), 335-354.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.

- Daya, H., Ashley, A., Gysin, C., & Papsin, B.C. (2000). Changes in educational placement and speech perception ability after cochlear implantation in children. *Journal of Otolaryngology*, 29(4), 224-28. Retrieved November 6, 2005, from http://www.childrenshearing.org/custom/research_articles.html#Pove.
- Denzin, N. K. (1994). The art and politics of interpretation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 500-515). Thousand Oaks, CA: Sage.
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2005). *Handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.
- DeVault, M. (1999). Talking and listening from women's standpoint: Feminist strategies for interviewing and analysis. In M. L. DeVault (Ed.), *Liberating methods: Feminism and social research* (pp. 59-83). Philadelphia: Temple University Press.
- Devlieger, P. J. (2000). Rejoinder: The culture and disability perspective on disability. *Disability and Rehabilitation*, 22(11), 526-527.
- Edwards, L. C. (2003). Candidacy and the children's implant profile: Is our selection appropriate? *International Journal of Audiology*, 42(7), 426-431.
- Emden, C. (1998a). Conducting a narrative analysis. *Collegian*, 5(3), 34-39.
- Emden, C. (1998b). Theoretical perspectives on narrative inquiry. *Collegian*, 5(2), 30-35.
- Emden, C., & Sandelowski, M. (1999). The good, the bad and the relative: Part two: Goodness and the criterion problem in qualitative research. *International Journal of Nursing Practice*, 5, 2-7.
- Finlay, F., & Gough, B. (Eds.). (2003). *Reflexivity: A practical guide for researchers in health and social sciences*. Malden, MA: Blackwell.
- Folkman, S., & Tedlie Moskowitz, J. (2000). Positive affect and the other side of coping. *American Psychologist*, 55(6), 647-654.
- Fraser, H. (2004). Doing narrative research: Analysing personal stories line by line. *Qualitative Social Work*, 3(2), 179-201.
- Frid, I., Ohlen, J., & Bergbom, I. (2000). On the use of narratives in nursing research. *Journal of Advanced Nursing*, 32(3), 695-703.
- Geers, A. (2003). Background and educational characteristics of prelingually deaf children implanted by five years of age. *Ear Hear*, 24(1), 2S-14S.
- Gibson, C. H. (1995). The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing*, 21, 1201-1210.

- Gray, D. (2003). Gender and coping: the parents of children with high functioning autism. *Social Science and Medicine*, 56, 631-642.
- Green, S. (2004). Attitudes toward control in uncontrollable situations: The multidimensional impact of health locus of control on the well-being of mothers of children with disabilities. *Sociological Inquiry*, 74(1), 20-49.
- Hall, J. M., & Stevens, P. E. (1991). Rigor in feminist research. *Advances in Nursing Science*, 13(3), 16-29.
- Hartrick, G. A. (1996). The experience of self for women who are mothers: Implications for the unfolding of health. *Journal of Holistic Nursing*, 14(4), 316-331.
- Harvey-Vallender, J. (2005). Becoming a mother was a difficult, multifactoral process. *Evidence-Based Nursing*, 1(1), 27.
- Hehar, S. S., Nikolopoulos, T. P., Gibbin, K. P., & O'Donoghue, G. M. (2002). Surgery and functional outcomes in deaf children receiving cochlear implants before age 2 years. *Archives of Otolaryngology: Head and Neck Surgery*, 128(1), 11-14.
- Helitzer, D. L., Cunningham-Sabo, L. D., VanLeit, B., & Crowe, T. K. (2002). Perceived changes in self-image and coping strategies of mothers of children with disabilities. *The Occupational Therapy Journal of Research*, 22(1), 25-33.
- Houston, D. M., Ying, E. A., Pisoni, B. P., & Iler Kirk, K. (n.d.). Development of pre-word-learning skills in infants with cochlear implants. *The Volta Review*, 103(4), 303-326.
- Iler Kirk, K., Miyamoto, R. T., Ying, E. A., Perdew, A. E., & Zuganelis, H. (2002). Cochlear implantation in young children: Effects of age at implantation and communication mode. *The Volta Review*, 102(4), 127-144.
- Jacelon, C. S., & O'Dell, K. K. (2005). Demystifying nursing research: Analyzing qualitative data. *Urologic Nursing*, 25(3), 217-220.
- Josselson, R., Lieblich, A., & McAdams, D. P. (Eds.). (2003). *Up close and personal: The teaching and learning of narrative research*. Washington, DC: American Psychological Association.
- Koch, T. (1998). Story telling: Is it really research. *Journal of Advanced Nursing*, 28(6), 1182-1190.
- Kubo, T., Matsuura, S., & Iwaki, T. (2005). Complications of cochlear implantation surgery. *Operative Techniques in Otolaryngology*, 16, 154-158.
- Kurtzer-White, E., & Luterman, D. (2003). Families and children with hearing loss: Grief and coping. *Mental Retardation and Developmental Disabilities Research Reviews*, 9, 232-235.

- Kvale, S. (1996). Methods of analysis. In S. Kvale (Ed.), *Interviews. An introduction to qualitative research interviewing* (pp. 187-209). Thousand Oaks, CA: Sage.
- Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science & Medicine*, 47(7), 865-875.
- Laughton, J. (1997). Educating children who are deaf or hard of hearing: Cochlear implants. *ERIC Digest #E554*. Retrieved November 7, 2005, from <http://www.ericdigests.org/1998-2/implants.htm>
- LeCompte, M. D. (2000). Analysing qualitative data. *Theory Into Practice*, 39(3), 146-154.
- Leslie, H., & McAllister, M. (2002). The benefits of being a nurse in critical social research practice. *Qualitative Health Research*, 12(5), 700-712.
- Levy, N. (2002). Reconsidering cochlear implants: The lessons of Martha's vineyard. *Bioethics*, 16(2), 134-153.
- Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (1998). *Narrative research: Reading, analysis, and interpretation*. Thousand Oaks, CA: Sage.
- Lincoln, Y., & Denzin, N. (1994). The fifth moment. In Y. Lincoln & N. Denzin (Eds.), *The handbook of qualitative research* (pp. 575-586). Thousand Oaks, CA: Sage.
- LoBiondo-Wood, G., & Haber, J. (1998). *Nursing research: Methods, critical appraisal, and utilization* (4th ed.). St Louis: Mosby.
- Luterman, D. (2003). Counselling families of children with hearing loss and special needs. *The Volta Review*, 104(4), 215-220.
- McCance, T. V., McKenna, H. P., & Boore, J. R. (2001). Exploring caring using narrative methodology: An analysis of the approach. *Journal of Advanced Nursing*, 33(3), 350-356.
- McGuire, B. K., Crowe, T. K., Law, M., & VanLeit, B. (2004). Mothers of children with disabilities: Occupational concerns and solutions. *OTJR: Occupation, Participation, and Health*, 24(2), 54-63.
- McKay, E., Ryan, S., & Sumsion, T. (2003). Three journeys towards reflexivity. In F. Finlay & B. Gough (Eds.), *Reflexivity: A practical guide for researchers in health and social sciences* (pp. 52-65). Malden, MA: Blackwell.
- McKeeve, P., & Miller, K. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science and Medicine*, 59, 1177-1191.
- McLeod, J. (1997). *Narrative and psychotherapy*. Thousand Oaks, CA: Sage.

- Mercer, R. T. (2004). Becoming a mother versus maternal role attainment. *Journal of Nursing Scholarship, 36*(3), 226-232.
- Merriam-Webster Online. (2007). *Experience*. Retrieved May 15, 2007, from <http://www.m-w.com/dictionary/experience>
- Milliken, J., & Rodney, P. (2003). Parents as caregivers for children with schizophrenia: Moral dilemmas and moral agency. *Issues in Mental Health Nursing, 24*, 757-773.
- Mishler, E. G. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University Press.
- Mitchell, W. J. T. (Ed.). (1981). *On narrative*. Chicago: University of Chicago Press.
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52*(2), 250-260.
- Morrow, S. L. (2007). Qualitative research in counseling psychology: Conceptual foundations. *The Counseling Psychologist, 35*(2), 209-235.
- Most, Y., & Zaidman-Zait, A. (2001). The needs of parents of children with cochlear implants. *The Volta Review, 103*(2), 99-113.
- Murray, M. (2003) Narrative psychology and narrative analysis. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology* (pp. 95-112). Washington, DC: American Psychological Association.
- Neill, J. (2002). Transcendence and transformation in the life patterns of women living with rheumatoid arthritis. *Advanced Nursing Science, 24*(4), 27-47.
- Nelson, A. (2002). A metasynthesis: Mothering other-than-normal children. *Qualitative Health Research, 12*(4), 515-530.
- Nicholas, J. G., & Geers, A. E. (2003). Personal, social, and family adjustment in school-aged children with a cochlear implant. *Ear and Hearing, 24*(1), 69S-81S.
- Nikolopoulos, T P., Lloyd, H., Archbold, S., & O'Donoghue, G. M. (2001). Pediatric cochlear implantation: The parents' perspective. *Archives of Otolaryngology: Head and Neck Surgery, 127*, 363-367.
- Nikolopoulos, T. P., O'Donoghue, G. M., & Archbold, S. (1999). Age at implantation: Its importance in pediatric cochlear implantation. *The Laryngoscope, 109*, 595-599.
- Oakley, A. (1979). *Becoming a mother*. Oxford: Martin Robertson.
- Oakley, A. (1990). Interviewing women: A contradiction in terms. In H. Robert (Ed.), *Doing feminist research* (pp. 30-61). London: Routledge.

- O'Brien, V. J. (2004). The relationship between family routines and perceived stress in mothers with children with and without disability. Doctoral dissertation, University of Southern California (UMI Order AAL3145255). Retrieved August 19, 2005, from EBSCOhost Web site: <http://search.epnet.com.ezproxy.library.uvic.ca/login.aspx?direct=true&db=cin20&an=2005122347>
- Oekerman, R. (2001). Children with special needs: Helping parents through the grief. *Texas Child Care, 25*(1), 10-13.
- Overcash, J. A. (2004). Narrative research: A viable methodology for clinical nursing. *Nursing Forum, 39*(1), 15-22.
- Pedersen, C. B., Jochumsen, U., Madsen, S., Koefoed-Nielsen, B., & Johansen, L. V. (2000). Results and experience of 50 cochlear implant operations. *Acta Otolaryngology, 543*, 147-150.
- Pelchat, D., Lefebvre, H., & Perreault, M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care, 7*(4), 231-247.
- Poirier, S., & Ayres, L. (1997). Endings, secrets, and silences: Overreading in narrative inquiry. *Research in Nursing & Health, 20*, 551-557.
- Preisler, G., Tvingsted, A. L., & Ahlstrom, M. (2002). A psychosocial follow-up study of deaf preschool children using cochlear implants. *Child: Care, Health, & Development, 28*(5), 403-418.
- Preisler, G., Tvingsted, A. L., & Ahlstrom, M. (2005). Interview with deaf children about their experiences using cochlear implants. *American Annals of the Deaf, 150*(3), 260-267.
- Priest, H., Roberts, P., & Woods, L. (2002). An overview of three different approaches to the interpretation of qualitative data. Part 1: Theoretical issues. *Nurse Researcher, 10*(1), 30-42.
- Reisz, E. D. (2004). Loss and transitions: A 30-year perspective on life with a child who has down syndrome. *Journal of Loss and Trauma, 9*, 371-382.
- Riessman, C. K. (1993). *Narrative analysis*. Newbury Park, CA: Sage.
- Rogan, F., Schmied, V., Barclay, L., Everitt, L., & Wyllie, A. (1997). 'Becoming a mother': Developing a new theory of early motherhood. *Journal of Advanced Nursing, 25*, 887-885.
- Rolfe, G. (2004). Validity, trustworthiness, and rigour: Quality and the idea of qualitative research. *Journal of Advanced Nursing, 53*(3), 304-310.

- Russell, K. E., & Coffin, C. (1999). Cochlear implants and the deaf child: A nursing perspective. *Pediatric Nursing*, 25(4), 396-401.
- Sach, T. H., & Whynes, D. K. (2005). Paediatric cochlear implantation: The views of parents. *International Journal of Audiology*, 44(7), 400-407.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37.
- Sandelowski, M. (1995). Focus on qualitative methods: Sample size in qualitative research. *Research in Nursing & Health*, 18, 179-183.
- Sandelowski, M., & Barroso, J. (2002). Reading qualitative studies. *International Journal of Qualitative Methods*, 1 (1), Article 5. Retrieved January 20, 2002, from <http://www.ualberta.ca/~ijqm/>
- Schwartz, C. E., & Sendor, R. M. (1999). Helping others helps oneself: Response shift effects in peer support. *Social Science & Medicine*, 48, 1563-1575.
- Seabrook, J., & Rodda, M. (1991). Parental response to deafness: How can we help? *ACEHI Journal*, 17(2), 64-70.
- Stallings, L. M., Iler Kirk, K., Chin, S. B., & Gao, S. (2002). Parent word familiarity and the language development of pediatric cochlear implant users. *The Volta Review*, 102(4), 237-258.
- Taanila, A., Syrjala, L., Kokkonen, J., & Jarvelin, M. R. (2002). Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health, & Development*, 28(1), 73-86.
- Tucker, B. P (1998). Deaf culture, cochlear implants, and elective disability. *Hastings Center Report*, 28(4), 6-14.
- Tye-Murray, N. (2003). Conversational fluency of children who use cochlear implants. *Ear Hear*, 24(1), 82S-90S.
- Wade, G. (1998). A concept analysis of personal transformation. *Journal of Advanced Nursing*, 28(4), 713-719.
- Watson, L., & Gregory, S. (2005). Non-use of cochlear implants in children: Child and parent perspectives. *Deafness and Education International*, 7(1), 43-58.
- Weisel, A., Most, T., & Michael, R. (2007). Mothers' stress and expectations as a function of time since child's cochlear implantation. *Journal of Deaf Studies and Deaf Education*, 12(1), 55-64.
- Wellard, S., & McKenna, L. (2001). Turning tapes into text: Issues surrounding the transcription of interviews. *Contemporary Nurse*, 11(2-3), 180-186.

- Whittemore, R., Chase, S., & Mandle, C. L. (2001). Pearls, pith, and provocation: Validity in qualitative research. *Qualitative Health Research, 11*(4), 522-537.
- Wicks, A., & Whiteford, G. (2006). Conceptual and practical issues in qualitative research: Reflections on a life-history study. *Scandinavian Journal of Occupational Therapy, 13*, 94-100.
- Williams, D. (1999). Human responses to change. *Futures, 31*(6), 609-616. Retrieved September 6, 2007, from <http://www.eoslifework.co.uk/futures.htm>
- Zaidman-Zait, A. (2007). Parenting a child with a cochlear implant: A critical incident study. *Journal of Deaf Studies and Deaf Education, 12*(2), 221-241.
- Zaidman-Zait, A., & Most, Y. (2005). Cochlear implants in children with hearing loss: Maternal expectations and impact on the family. *The Volta Review, 105*(2), 129-150.

APPENDIX A: COCHLEAR IMPLANTATION AND HOW IT WORKS

Cochlear implantation (CI) is a technology that has been in use for over two decades in the treatment of people with a severe to profound sensorineural hearing loss (Callanan & O'Connor, 1996; Russell & Coffin, 1999). A deaf child received a cochlear implant for the first time in the early 1980s; since that time there have been great improvements and changes in this potentially life-altering process (Bionic Ear Institute, 2006; Russell & Coffin, 1999). By the end of 2000 approximately 20,000 children worldwide had received cochlear implants (Watson & Gregory, 2005).

Many consider cochlear implantation the first major advance in 200 years, since signing was established at the Paris Deaf School (Bionic Ear Institute, 2006), in helping profoundly deaf children to communicate. Russell and Coffin (1999) believed that CI has significantly assisted children who are deaf to realize their maximum potential in the hearing world. However, some, particularly from the Deaf community, do not agree with paediatric CI. Such individuals go as far as to charge that the use of cochlear implants is unethical and nothing less than a form of cultural genocide (Levy, 2002; Russell & Coffin, 1999; Tucker, 1998).

How a Cochlear Implant Works

Cochlear implants are neural prosthetic devices that present electronic equivalents of the speech signal to a nonfunctioning auditory system (Nikolopoulos et al., 1999). The technology works by directly stimulating the auditory nerve fibres in the inner ear or cochlea, which ultimately helps people who are deaf to perceive environmental sounds, recognize words and sentences, and improve their audiovisual perception of speech

(Callanan & O'Connor, 1996; Russell & Coffin, 1999). The implant system consists of a surgically implanted internal unit that includes a receiver and an electrode array, and an external component that processes or codes acoustic signals and then transmits them to the receiver. The transmitter (the external component) and receiver (the internal component) are held in position by a magnet, which enables the FM signal to pass through the skin to the receiver and directly stimulates the cochlear nerve, thereby restoring the sensation of hearing (Callanan & O'Connor, 1996).

APPENDIX B:
DEFINITION OF TERMS

1. Dominant ideologies: Concepts, ideas, and beliefs that are constructed by a dominant group within a society and have the greatest influence in determining a culture's overall outlook. They legitimize what is seen as right, good, and *normal*. Therefore, all morality confirms this view, and all social structure sustains it (Miller; as cited in Oakley, 1990, p. 40).
2. Data saturation: The collection of data until no new information is obtained. It may be used to justify the type, relative depth, and extent of the data collection (Denzin & Lincoln, 2005).
3. Interpretive sufficiency: A criterion of data collection that takes into account cultural complexity and multiple interpretations of life (Denzin & Lincoln, 2005).
4. Purposive sampling: A strategy used to include selected participants in a research study by handpicking them based on specific characteristics. It is most often used when a highly unusual group is being studied (LoBiondo-Wood & Haber, 1998).
5. Cyclical grieving: An intermittent reoccurrence of one or more emotions that are part of the grieving process. In the case of this study, it is the emotions that parents of children with disabilities experience (Blaska, 1998).
6. Disabled/disability: Someone who may be other than what is typically viewed as normal. It is a culturally created phenomenon that is both time and place dependent. Consequently, disability may take on different meanings from one social group to another as well as from one historical period to another (Devlieger, 2000).

7. Grief/grieving: A process in response to a significant loss. Stages of grief typically include denial, anger, bargaining, depression, and acceptance (Oekerman, 2001).
8. Reflexive approach: A practice that allows researchers to reflect on subjective thoughts and feelings that occur during the research process. It situates the researcher and his or her knowledge-making practices within relevant contexts (Finlay & Gough, 2003).
9. Prelingually deaf: The onset of deafness before oral language is learned, usually by two years of age.

APPENDIX C:
POTENTIAL BENEFITS AND COMPLICATIONS
OF COCHLEAR IMPLANTATION

Potential benefits

- Ability to detect conversational sounds including speech at comfortable levels of loudness
- Ability to identify everyday environmental sounds such as motor vehicles, horns, door bells, birds singing,
- Improved lip-reading skills
- Recognition of speech without lip reading
- Improvements in speech
- Improvement in the audiovisual perception of speech
- Appreciation of music
- Ability to use telephone without assistance
- Increase in confidence and communication
- Decrease in loneliness and social anxiety

Potential complications or adverse effects

- Inappropriate placement of the electrode array (internal component)
- Transient facial nerve palsy
- Partial device extrusion
- Flap necrosis
- Electrode migration
- Cochlear perforation

- Cerebral spinal fluid leak
- Meningitis
- Resection of the chorda tympani nerve resulting in temporary or permanent mouth dryness or taste disturbances
- Device failure
- Complications that come with any surgical procedure such as infection and anesthesia
- Wound breakdown requiring removal of the implant
- Dependency on technology
- Cost of upkeep: replacement parts, batteries
- Need for long term support with CI center

(Archbold et al., 2002; Callanan & O'Connor, 1996; Nicholas & Geers, 2003; Russell & Coffin, 1999)

APPENDIX D:
CRITERIA FOR COCHLEAR IMPLANTATION CANDIDACY
AT B.C. CHILDREN'S HOSPITAL

Who is a pediatric candidate for a Cochlear Implant?

- 12 months to 16 years of age
- bilateral severe to profound sensorineural hearing loss (exception: 12-18 month olds require bilateral profound sensorineural hearing loss)
- little or no benefit from hearing aids as determined through a trial period with consistent binaural amplification (3-6 months)
- inner ear capable of accommodation the internal device
- no medical contraindications, i.e., active middle ear infection, ossification, etc.
- family support in place
- realistic expectations
- enrolment in an educational/habilitation program with emphasis on auditory/oral development

* No patient will be accepted as a CI candidate if he/she does not have a primary habilitationist. No CI surgery will take place until this has been established and surgery could be delayed in order to ensure that this critical piece has been addressed. (C. Juck, personal communication, May 2006)

APPENDIX E:
LETTER TO RESOURCE CENTRE

To: [Individual's name] [Date]

[Title]

[Resource center name]

Dear [Individual's name],

My name is Shelley Berezon I am a graduate student at the University of Victoria in the School of Nursing, Studies in Policy and Practice. As a graduate student, I am required to conduct research as part of the requirements for a degree in Nursing. It is being conducted under the supervision of Dr. Elizabeth Banister. You may contact my supervisor at (250) 472-4703. You may also verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4545).

The purpose of this research project is to gain a better understanding of mothers' experiences while their child undergoes the cochlear implantation process. Research of this type is important because right now there is very little information about the experiences a mother goes through. It is also needed to inform the professionals who work with these families.

This letter is to request your assistance in informing potential mothers to participate in this study. I am looking for mothers whose child has received a cochlear implant when he/she was between 2 to 5 years of age and no less than 8 months at the time of the interview. The interviews will take place between July and September 2006.

I will contact you by telephone in one-week time to follow up. If this is something that you are interested in assisting with we can discuss feasible options for informing the mothers who fit the criteria associated with you centre.

The mothers' involvement in this research must be totally voluntary. Her participation will include a one and a half to two hour (1 ½ - 2 hr) interview in her home or a mutually agreed upon location. She will also be invited to read over the written transcription of her interview to help ensure that I have captured her stories as accurately as possible. She may withdraw at any time without any consequences or any explanation. If she does withdraw from the study her data will not be used.

Participation in this study may cause some inconvenience to the mother including her time (the time it will take to be interviewed, to read through the transcript make any changes or corrections as she sees fit), and the need to secure childcare during the interview. As a way to compensate for any inconvenience related to her participation, I

will offer to cover the cost of childcare if it is needed for a maximum of \$25.00 per interview. It is important however that she knows that it is unethical to provide undue compensation or inducements to research participants and if she agrees to be a participant in this study, this form of compensation to her must not be coercive. If she would have not chosen to participate if the compensation was not offered, then she should decline.

There are some potential risks to the mother's by participating in this research. Because of the sensitive nature of the topics painful emotions might be aroused. To prevent or to deal with these risks the following steps will be taken: I will ask if her if she would like to take a break or move on to a different focus. If distressed I will stop the interview and stay with her until I am assured that she is less distressed. If needed I will connect her with a local counsellor if she do not already have one. With her permission I will also call her either later in the day or the following day.

The potential benefits for the mother's participation in this research include an increased self-awareness and sense of empowerment. Her participation may also give voice to her experience and may foster a sense of connectedness with the other mothers who have children undergoing cochlear implantation.

In terms of protecting the mother's anonymity I will use pseudonyms or aliases. To ensure other recognizing details are protected I will use fictionalizing methods for any areas the mother may wish to be changed. She will have the opportunity at any time to withdraw any information she may have revealed.

The mother's confidentiality, and the confidentiality of the data, will be further protected by keeping all forms of research documentation (audiotapes, papers, records) locked in a drawer. Only myself, and my supervisor Dr. Banister, will have access to this information.

It is anticipated that the results of this study will be shared with others in the following ways: directly to all participants in the study; in my thesis presentation; presentations at scholarly meetings and conferences; published scholarly articles.

Data from this study will be disposed of three years following the completion of the graduate thesis process. At that time I will erase all audio taped interviews, clear all computer files and disks, shred all transcripts and relevant papers.

It is my hope that you will assist me in this very important research study. I look forward to hearing from you. You may reach me by phone at either xxx-xxxx or xxx-xxxx, or by email sberezon@uvic.ca. Thank you for your attention.

Sincerely,

Shelley Berezon RN, BSN, MN (c)

APPENDIX F: PARTICIPANT CONSENT FORM

You are being invited to participate in a study entitled “My child has a cochlear implant”: Mothers’ Stories that is being conducted by Shelley Berezon.

Shelley Berezon is a graduate student in the department of Nursing at the University of Victoria and you may contact me if you have further questions by calling (250) xxx-xxxx.

As a graduate student, I am required to conduct research as part of the requirements for a degree in Nursing. It is being conducted under the supervision of Dr. Elizabeth Banister. You may contact my supervisor at (250) 472-4703.

The purpose of this research project is to gain a better understanding of mothers’ experiences while their child undergoes the cochlear implantation process.

Research of this type is important because there is very little information about the experiences a mother goes through related to her child’s cochlear implantation. It is also needed to inform the professionals who work with these families.

You are being asked to participate in this study because you are a mother whose child has received a cochlear implant when he/she was between 2 to 5 years of age and no less than 8 months prior to the time of the interview.

If you agree to voluntarily participate in this research, your involvement will include partaking in a one and a half to two hour (1 ½ - 2 hr) interview in your home or a mutually agreed upon location. You will also be invited to read over the written transcription of your interview and provide input into the transcripts as you see fit. This credibility check is used in research to help ensure that I have captured your stories as accurately as possible. Transcript changes can be communicated to me however most convenient for you: telephone, email or surface mail at my expense.

Participation in this study may cause some inconvenience to you including your time (the time it will take to be interviewed, and if you agree to do so, to read through the transcript make any changes or corrections); and the need to secure childcare during the interview.

There are some potential risks to you by participating in this research. Because of the sensitive nature of the topic you may develop some uncomfortable or painful emotions. If this should occur the following steps will be taken: I will ask if you would like to take a break or move on to a different focus. If needed I will end the interview and remain with you until I am assured that you are feeling less distressed. If needed I will connect you with a local counsellor if you do not already have one. With your permission I will call you either later in the day or the following day.

The potential benefits for your participation in this research include an increased self-awareness and sense of empowerment. Your participation may also give voice to your

experience and may foster a sense of connectedness with the other mothers who have children undergoing cochlear implantation.

As a way to compensate you for any inconvenience related to your participation, if you are needing to pay for childcare during the interview you will be provided with a maximum of \$25.00 per interview to help cover the cost. It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive. If you would not otherwise choose to participate if the compensation was not offered, then you should decline.

Your participation in this research must be completely voluntary. If you do decide to participate you may withdraw at any time without any consequence or any explanation. If you do decide to withdraw from the study your data will not be used.

In terms of protecting your anonymity I will use pseudonyms and or aliases. To ensure other recognizing details are protected I will use fictionalizing methods for any areas you may wish to be changed. You have the opportunity at any time to withdraw any information you have revealed.

Your confidentiality, and the confidentiality of the data, will be protected by keeping all forms of research documentation (audiotapes, papers, records) in a locked drawer. Only I, and my supervisor Dr. Banister, will have access to this information.

It is anticipated that the results of this study will be shared with others in the following ways: directly to all participants in the study; in my thesis presentation; presentations at scholarly meetings and conferences; published scholarly articles.

Data from this study will be disposed of three years following the completion of the graduate thesis process. At that time I will erase all audio taped interviews, clear all computer files and disks, shred all transcripts and relevant papers.

In addition to being able to contact the researcher and the supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4545).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
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A copy of this consent will be left with you, and a copy will be taken by the researcher.

APPENDIX G:
INTERVIEW GUIDE: QUESTIONS

Main query:

Tell me about what it was like for you when your child was going through the process of getting his/her cochlear implant.

Inviting questions:

1. How did you decide that your child would benefit from a CI?
2. What did you experience once your decision was made?
3. How did you prepare yourself for the surgery?
4. Tell me about the day of the surgery? What was it like for you?
5. What was it like for you the day your son/daughter's processor was turned on?
6. Describe a typical day during the early days of habilitation.

Probing questions:

1. Tell me about the time that . . .
2. Tell me what happened, starting from the beginning.
3. Is there a specific incident you can think of that would make clear what you have in mind.

Near the end of the interview:

Do you think that your health and well being has been effected by your experiences of having a child who has gone through this process? How so?