

Grief in the Context of Early Hearing Detection and Intervention Programs:

Parents' Perceptions of Grief Processing and Support

By

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Abstract:

The purpose of this qualitative research study was to gain an understanding of parental grief experiences within the context of an early hearing detection and intervention program and to examine parents' perception of the professional support they received. Through focus group interviews, eight mothers and seven fathers, whose infants were diagnosed with a hearing loss at birth through a universal newborn hearing screening and who were confronted immediately with a health care system necessitating decisions about early intervention, were invited to share their emotional journey and their experiences of being supported. Parents shared emotions associated with grief and processing grief, their emotional and informational needs, and what influenced their decision making process. Differences between spouses were also examined.

The findings are presented through three central themes. The first theme revealed that grief was a part of parents' emotional journey. Specifically parents shared feelings of grief related to the loss of what they had anticipated, and mothers shared feelings of loss associated with their anticipated experience of motherhood. The grief experience was different for mothers and fathers. The second theme revealed that as parents processed their grief, they experienced a paradox of emotionally moving forward and staying in place. Parents shared feelings of happiness and joy when they spoke about their children yet they also shared experiences that reflected a continuance of grieving. The final theme indicated the ways in which parents discussed being emotionally supported and the differences in support needs between husbands and wives.

The discussion of these themes addressed the paradoxes that existed and the notion that parents were uncomfortable living with these paradoxes. Implications for professionals who support parents throughout their EHDI program experience were also described, including the provision of information and how that information impacts parents' need for emotional support. The implication that professionals must provide parents the space to feel their emotions related to grief was also explored.

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Table of Contents

LIST OF TABLES	VII
CHAPTER 1 - INTRODUCTION	1
Statement of the Problem.....	1
Overview of the study.....	6
CHAPTER 2 - LITERATURE REVIEW.....	8
Understanding Grief	8
Grief Theories	12
Processing Grief	16
Reaction to the Diagnosis of a Hearing Loss	21
Evidence for the Existence of Grief	23
Newborn diagnosis.	24
Diagnostic process.....	25
Outcomes of hearing loss.....	27
Decision making.....	29
Supporting Families through their Grief.....	30
Informational support.	33
Counseling and emotional support.	35
CHAPTER 3- METHODS.....	39
Role of the researcher	40
Locating the Research and Research Participants.....	42
Description of Participants.....	45
Data Collection.....	48
Focus groups.	49
Child language observation and interaction.....	51
Data Analysis	53
Credibility and trustworthiness	55
CHAPTER 4- FAMILY PROFILE.....	58

Claire and Eric.....	58
Val and James	59
Zoe.....	60
Rachael and Chris.....	60
Elizabeth and Rob.....	61
Hannah and Jason.....	62
Julia and Adam.....	63
Christina and Derek.....	64
 CHAPTER 5 - FINDINGS	 65
Theme 1: Grief Related to Loss	66
Grief for the apparent loss of what was envisioned.....	67
Grief for the loss of the anticipated experience of motherhood.	69
Different grief reactions in husbands and wives.	72
Summary.	75
Theme 2: Paradoxes in Processing Grief - Moving forward and Staying in Place	76
Emotionally moving forward.	76
Embracing their child.....	76
Gaining a sense of control.....	79
The new normal.	82
Awareness of child’s skills and potential challenges.....	83
Summary.	84
Staying in place - continued grieving.	85
Outcome focused.	86
Isolation.....	91
Brought back to grief.	96
Summary.	100
Theme 3: Being Cared for Emotionally.....	101
Initial Support.....	101
Qualities of supporting professionals.	103
Accepting less.....	107
Supporting each other.	108
Summary.	110
Conclusion	110
 CHAPTER 6 - DISCUSSION.....	 112

Grief in the Context of EHDI.....	112
Explaining the Paradox.....	113
Building the meaning of Deafness	119
Support.....	122
Implications.....	126
Limitations	130
Conclusion	133
REFERENCES.....	135
APPENDIX A	154
APPENDIX B	156
APPENDIX C	158
APPENDIX D	161
APPENDIX E.....	162

List of Tables

Table 1.	46
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Chapter 1 - Introduction

Statement of the Problem

The focus of this research is on hearing parents whose children are diagnosed with a hearing loss through an Early Hearing Detection and Intervention (EHDI) program. EHDI programs are comprised of universal newborn hearing screening (UNHS), timely diagnostics, and facilitation to intervention programs or communication/developmental services (Finitzo & Crumley, 2000). While they have become the standard of care in hospitals all over the United States and the United Kingdom, many Canadian provinces have no EHDI program or have locally initiated efforts that in some areas include only the screening portion of the overall comprehensive EHDI program. The objectives of these programs are to screen infants at birth for hearing loss, confirm the diagnosis by three months of age, and ensure that infants are enrolled into early intervention by six months of age (Durieux-Smith, Seewald, & Hyde, 2000). In addition to the one-three-six month timeline of EHDI programs, other important components involve the provision of family support, and unbiased information in the context of a family-centered model of service delivery.

Research has addressed some of these component areas: screening, diagnosis, and intervention. The practicality, feasibility, and cost effectiveness of universal newborn hearing screening has been well addressed in the literature as has best practices for diagnostic procedures. Yoshinaga-Itano and her colleagues have led research studies demonstrating that children who receive early intervention by six months achieve age appropriate language milestones by their second or third year of life regardless of communication modality (Yoshinaga-Itano, 2003). There have also been studies

examining parents' perspectives of their experiences of EHDI programs some of which address one specific component. These could be the screening (Poon, 2005); maternal anxiety regarding the screening (Clemens & Davis, 2001; Hergils & Hergils, 2000; Poulakis, Barker, & Wake, 2003; Weichbold & Welzl-Mueller, 2001; Weichbold, Welzl-Mueller, & Mussbacher, 2001), reacting to the diagnosis (Tattersall & Young, 2006), or the overall EHDI experience (DesGeorge, 2003; Kelly & Bibby, 2008). While evidence supports the contention that a newborn's hearing can be screened and a hearing loss can be identified, without appropriate support services in place the advantages of early detection are not utilized to their full potential (Young, Jones, Starmer, & Sutherland, 2005; Yoshinaga-Itano, 2003).

Researchers are beginning to clearly highlight the need for more research addressing parental adjustment to hearing loss in the context of EHDI programs and the quality of life issues that can influence the process (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007). Adjustment has been a key component in the disability literature examined through a variety of theoretical frameworks (Young, 1999). Many of these frameworks have focused on negative parental adjustment, such as grief and sorrow, and have been criticized for this pathological focus (Kandel & Merrick, 2007, Young, 1999). Other frameworks, such as models of stress and coping or family system theories have been employed to highlight positive adjustments focusing on issues such as family strengths and family resiliency (Lynch, & Morley, 1995; Trute, Hiebert-Murphy, & Levine, 2007). Addressing adjustment to hearing loss in the context of EHDI is significant because EHDI programs bring about a change in the ways parents come to know about their child's hearing loss. In the context of EHDI programs parents learn of

their child's hearing loss at birth. This has raised the concern that parents no longer have the time to simply get to know their child and adjust to being a new parent before they encounter a new and slightly more complicated reality. Being faced with a different-than-expected reality has the potential to affect parents' subsequent interactions and ability to make decisions on behalf of their child (Fitzpatrick et al., 2007, Young & Tattersall, 2007). Parents have not prepared themselves for a reality that involves immediately linking to a health care system and an education/intervention system with which they have most likely not had any prior experience. Parents have not prepared themselves to make immediate decisions about technology, intervention-placement options, and communication approaches. Parents have not considered forming relationships with a variety of professionals, with varying opinions, who they will turn to for assistance in making their decisions. All of these elements become part of their new reality.

Currently there is little research concerning how these changes specifically influence parental adjustment. There is some research which suggests that early identification enables parents to more quickly resolve feelings of grief (Siegle, 2000 as cited in Yoshinaga-Itano & de Uzcategui, 2001). Such claims required further investigation and served as the impetus for examining parental adjustment in the form of grief in the current study. It should be noted that it is not the researcher's belief that grief is the only or the guaranteed reaction for all parents whose children are diagnosed with a hearing loss. For example, a Deaf parent may have an entirely different reaction to their child's hearing loss as compared to a parent who is hearing. But as Young and Tattersall (2007) concluded the grief felt by parents whose children were diagnosed with a hearing

loss through an EHDI program can be a, “powerful psychological and emotional response that influences parental behaviour and decision making” (p. 217).

The grief literature highlights the complexity of grief and presents a myriad of definitions. Grief can be defined as “an emotional response, a series of stages and phases, an illness, a series of tasks, an active process of coping, a spiritual journey, or a uniquely personal experience” (Gilbert, 2007). Disability-related grief is a concept that has not obtained consensus in the literature. Studies depend very much on the theoretical model of grief to which the researchers ascribe. The literature examining how families adjust to hearing loss through grief has defined grief as a series of stages or as being experienced chronically or infinitely (Kurtzer-White & Luterman, 2003). Studying grief in the context of EHDI programs without the application of a particular grief theory is important not only to find out from parents how they define their grief, but also to understand how parents are able to process their grief as they navigate their experiences in response to the diagnosis of their child’s hearing loss. Research has also examined familial factors that also influence the grief process; one of them surrounds the different way in which mothers and fathers experience grief and work to process their grief. Literature states that the way husbands and wives navigate the grief experience can either bring them closer together or put a strain on their marriage (Featherstone, 1981).

Researchers have just begun to explore how professionals are supporting and counseling grieving parents within these “changed circumstances” (Young & Tattersall, 2007, p.210) brought on by the implementation of EHDI. The provision of professional informational and emotional support cannot prevent families from grieving but it has the potential to ease their grief. In the deafness field, professionals from various disciplines

work together, with varying degrees of success. They aim to provide the best practice guideline of a seamless transition from diagnosis through early intervention, ensuring that the families' needs are met (Gallagher, Easterbrooks, & Malone, 2006). Research confirms that parents' reactions to the diagnosis of their child's disability are greatly influenced by the information and advice they receive from professionals who support them (Mitchell & Sloper, 2001). Many EHDI programs have created or incorporated a position of support worker or service coordinator to assist families as they transition from diagnosis through early intervention, working with them through their emotional reactions and their need for information enabling them to engage in decision-making. Yet some parent perspective studies indicated that parents have mixed feelings about the need and value of these positions (Fitzpatrick et al., 2008). Sometimes parents find that these professionals underestimate their need for emotional and informational support (Fitzpatrick et al., 2008; Graungaard & Skov, 2006; Worden, 2002). Literature from the perspective of the professionals also acknowledges that they have difficulty meeting parents' initial needs upon receiving their child's diagnosis (Graungaard & Skov, 2006).

While there have been studies that have examined parents' perceptions of the EHDI program experience, few studies have addressed the grief reaction, specifically how parents have been emotionally supported and provided with the information essential to them to make informed choices. The purpose of this study was to examine how parents described their emotional journey and how they were supported by professionals, who have helped or hindered their ability to overcome their grief and make the myriad decisions that face them.

Overview of the study

Using a phenomenological research design, this qualitative study was employed to gain an understanding of the parents' grief experience within the context of an EHDI program and to examine their perception of the professional support they received. Focus groups were conducted with 8 hearing families grouped by the gender of the participants. In other words, fathers were grouped with other fathers and mothers were grouped with other mothers. Analysis revealed three central themes surrounding the notion of grief and support. The first theme concerns the ways in which the parents experienced grief as a part of their initial reaction to their child's diagnosis. Parents shared their feelings of loss associated with a loss of what they had anticipated. Mothers in particular shared their perceived loss of the anticipated experience of motherhood. Mothers and fathers shared the ways in which their grief experience was different from that of their partner.

The second theme refers to the emotional paradox of the parents as they continued to process their grief. Parents shared feelings of happiness and joy when they spoke about their children and their child's successes. Parents spoke about processing their grief by gaining a sense of control. They also shared the positive ways in which they have come to view their child's diagnosis of hearing loss by coming to view it as a "new normal". They demonstrate an awareness of their child's skills and potential challenges. Yet while parents spoke about their joys they also shared experiences that reflected a continuance of grieving. Parents' shared experiences which reflected a greater focus on their child's developmental outcomes, and on social situations which resulted in their isolation, even if they had purposefully isolated themselves. Parents also addressed ways in which they felt a return to the initial feelings of grief.

The third theme refers to parents' experiences of emotional support. Parents in this study described their perception of the initial support they received; they identified positive qualities of supportive professionals. Parents demonstrated a willingness to accept substandard professional services and treatments. The different support needs between husbands and wives were also described.

The discussion of these themes addressed the paradoxes that existed and the notion that parents were uncomfortable living with these paradoxes. Implications for professionals who support parents throughout their EHDI program experience were also described. Careful consideration must be given to provision of the informational support offered to parents and how that information impacts their need for emotional support. The notion that professionals must provide parents the space to feel emotions related to grief was also explored.

Chapter 2 - Literature Review

How families react and adjust to the diagnosis of a child's disability is an individual and complicated process (Gilbert, 2001). There are both positive and negative means of adjusting to disability and grief was one aspect of adjustment chosen to examine this process from the various possibilities. Before proceeding in an examination of the literature pertaining to grief, the criticism in regards to using grief as a model for explaining adjustment should be acknowledged. Young (1999) explained that when grief is used to understand adjustment to hearing loss, it automatically assumes that hearing loss is a deficit, a tragedy that must be overcome. Examining adjustment from a pathological and negative perspective has also been criticized for enabling researchers to interpret positive narratives from parents as indicative of pathological responses such as denial (Trute, Hiebert-Murphy, & Levine, 2007). While these criticisms exist, they do not detract from the fact that grief is still a part of parents' narratives and worthy of analysis. This review will address grief and those factors that potentially influence how it is experienced and processed. Three different perspectives on grief will be described followed by a closer look at how grief is influenced by the diagnosis of hearing loss. While there is still much to know and understand about this process, the literature related to professionals supporting families, both through informational and emotional support will also be explored.

Understanding Grief

The definition of grief varies; there is no clear consensus about its meaning. Grief literature centres on loss: grief as a normal response to loss, as a healing response to loss, or as a response to a loss of meaning (Foley, 2006; Powers, 1993; Kandel & Merrick,

2003). The grieving process involves making sense of the loss (Attig, 1991; Neimeyer, 2001; Thompson, 2002). The emotions that have been used to characterize grief are feelings such as uncertainty, avoidance, shock, blame, numbness, disorientation, anger, sadness, fear, anxiety, guilt, longing, depression, aggression, anger, helplessness, acceptance, and integration (Fortier & Wanlass, 1984; Foley, 2006; George, Vickers, Wilkes, & Barton, 2006; Kandel & Merrick, 2007; MacGregor, 1994; Worden, 2002). Grief is also defined as being comprised of more than an emotional response; it is also comprised of physical reactions, thoughts, and behaviours (Stroek, Strobe, & Hansson, 1993; Worden, 2002). Research is conclusive on the complexity of the grief response. Grief is complicated, unique for every individual, confusing and confounding (Hansson, Carpenter, & Fairchild, 1993). While much of the grief literature has focused on grief in relation to the death of a parent, partner or child, there is some research that deals specifically with the grief felt by a parent whose child has been diagnosed with a disability. Disability-related grief is different from bereavement-related grief; in the former parents have difficulty understanding what is lost. As literature explains, the loss felt by these parents is for the child that they had envisioned having; for what they had hoped for their child to become; and for the role they envisioned having as parents (Featherstone, 1980; Hilton, 1993; Kandel & Merrick, 2003). Parents may feel guilty for grieving because, while they have not physically lost their child, they still experience these emotions (Kearney & Griffin, 2001). Foley has described this loss as a “loss less total and less final than loss by death, [but] nevertheless . . . no less real and perhaps no less painful” (2006, p.231). The disability-related grief reaction can be filled with disbelief, intense sadness, numbness, anxiety, fear, anger, denial, disappointment,

frustration, guilt, shame, and confusion (Boyd, 2001; Foley, 2006; Heiman, 2002; Hilton, 1993; Kandel & Merrick, 2003; Kearney & Griffin, 2001; Sloper & Turner, 1993).

There are many factors that influence how grief is experienced. Factors such as the characteristics of disability, child, parents, and family, as well as internal and external resources all impact feelings of grief. An extensive body of research addresses such factors and a thorough review of this literature is beyond the scope of this study.

However, the following highlights some of the essential components of the research regarding how families process the diagnosis of a disability (Boss, 2002; Ferguson, 2000; McCubbin & Patterson, 1983; Pelchat, Ricard, Bouchard, Perreault, Saucier, Berthiaume, Bisson, 1999; Hill, 1985). Characteristics pertinent to a particular disability influence how grief is experienced because different characteristics serve different roles in defining stressful situations (Pelchat, Ricard, Bouchard, Perreault, Saucier, Berthiaume, & Bisson, 1999). Factors that influence the impact on grief include: the chronic nature of the disability, the visibility, the degree of physical, intellectual and functional impairment, the necessity of surgical procedures, the degree of predictability in future development and independence, the degree that the disability impacts communication, the severity and the degree of complications and timing of the diagnosis (Hilton, 1993; Orme, 2005; Pelchat et al., 1999; Pianta, Marvin, & Morog, 1999). Clements, Copeland and Loftus (1990) reported that the majority of parents found the time of their child's diagnosis to be the most difficult period. Other studies describe parents feeling more grief when the diagnosis occurred at a later stage leaving them feeling that they should have known sooner (Powers, 1993).

Characteristics pertinent to child, parents and family that impact grief are influential because they impact what internal and external resources can be drawn upon as grief is experienced and processed. Internal resources such as individual temperament, belief systems, individual and family communication patterns, cultural style, perceptions of parental roles and disability can all impact grief (Cummings, Davis, & Campbell, 2000). For example, if a parent is in a depressive state prior to the birth of a child or if a parent experiences post-partum depression, their reaction to the diagnosis is influenced. Alternatively, if the child has a difficult temperament, a parent may feel more stressed in carrying out day-to-day parenting tasks and therefore have less coping capabilities to process the diagnosis of a disability. Associations have been examined between grief reactions and parental demographic characteristics including age and education, and the gender and age of the infant without any obvious conclusions (Seligman & Darling, 2007). External resources such as parental income level, the availability of support and the social environmental context are significant factors (Boss, 2002; Ferguson, 2000; McCubbin & Patterson, 1983; Reubin Hill, 1985). For example, studies have found that it is most common for mothers to stay home and for fathers to work outside the home (Featherstone, 1980). Families with higher income have been reported to experience less stress than those facing financial burdens (Scorgie, Wilgosh, & McDonald, 1998). Parents may also struggle in trying to determine their place in society and culture once becoming a “parent of a child with a disability” (Land, 1998).

The experience of grief can also vary based on the different perspectives of family members, i.e. mothers and fathers. Some research states that partners can have an expectation that they should go through the process with the same beliefs and the same

meanings attributed to their loss as their partner. They may have tremendous difficulty accepting when one is grieving in a way that is different from their own (Gilbert, 2001). Often this is not acknowledged and leads to distress, misunderstandings and marital strain. Research has indicated that mothers show more severe grief reactions than fathers; fathers appear to be more in control of their emotions, to suppress their feelings, and to use denial (Bohannon, 1990). Strain can result as husbands and wives try to negotiate how to have their own needs met, how to support each other and how to proceed with the next steps. Some research also indicates that the marital relationship can be strengthened as a result of a coming together, working together and celebrating the joyous moments in raising a child with a disability (Taanila, Kookonen, & Jaervelin, 1996).

Grief Theories

While there is a body of literature that examines the processing of grieving or adjusting to disability through the above mentioned factors, there is another body of knowledge that has examined and defined grief through a particular theoretical lens. This section will examine three popular perspectives that have been applied to disability-related grief with varying degrees of appeal and criticism. They include 1) time-bound or stage based, linear models of grief in which acceptance is a necessity to healthy adjustment and failure to accept loss is maladaptive and requires intervention; (Bowlby, 1980; Frontier & Wanlass, 1984; Kubler-Ross, 1969; Sander, 1992; Schneider, 1983), 2) theories that view grief as a chronic or reoccurring experience (Bruce & Schultz, 2001; Martin & Elder, 1993; Olshansky, 1962) and 3) theories that present parents' grief reactions as being comprised of simultaneous oppositional thoughts, i.e. joy and sorrow, or positivity and negativity.

Stage-based or time-bound perspectives have been developed and extended to account for the ways in which grief is experienced by parents in reaction to the diagnosis of their child's disability. Stage theories are meant to demonstrate that grief is a natural, common and expected reaction for parents upon receiving the diagnosis of their child's disability. These stage theories indicate that grief is time limited, with a start and end phase. Many similarly patterned stage theories identify a range of emotions through which parents work. Some authors have indicated that the sequence is variable and that stages should be applied in a flexible manner (Marshark & Prezant, 2007; Seligman & Darling, 2007). The common core stages involve: a period of "disbelief and initial awareness", followed by the "reactional phase" wherein families begin to acknowledge the situation and their needs, and lastly, the "constructive action" phase which results in acceptance (Friehe, Bloedow, Hesse, 2003, p 213). Examples of these theories include those of Kubler-Ross (1969), Bowlby (1980), Schneider (1983) and Worden (2002). Kubler-Ross' (1969) stage-based model describes a series of stages: denial, anger, bargaining, depression, and acceptance. Bowlby's (1980) attachment theory explains grief as an instinctive response to separation, describing parents who initially experience numbing, yearning and searching for the lost figure followed by disorganization, despair, and re-organization. Schneider's model (1983) is also a stage model, wherein parents initially go through a period of awareness, then attempt to overcome the loss, followed by an awareness of the extent and implications of the loss. The final stage is termed completion, resolution and reformulation. Worden (2002) developed a model, which described grief as a process and not a state. He proposed that families need to work through a series of tasks in order to make a complete adjustment.

Olshansky (1962) was the first to challenge the relevance of bereavement-related grief in relation to the diagnosis of a disability and introduced the concept of chronic sorrow. Theoretical models applying grief terms such as “episodic grief”, “chronic sorrow” (Olshansky, 1962), or “nonfinite grief” (Bruce & Schultz, 2001) have been most consistently applied to the grief reaction of families whose children are diagnosed with a disability. These models indicate that grief is not time limited. “Chronic sorrow” characterizes grief as a normal parental reaction to learning that an infant has a disability. It does not require that parents resolve their grief to avoid being labeled as pathological (Olshansky, 1962). “Nonfinite grief” also focuses on the notion that grief is never completely resolved. These theories describe recurring experiences of grief as being associated with “the discovery of new medical problems, the unending caregiving responsibilities, the unpredictable nature of their child’s illness, complications, uncertainty”, and “when the child struggles to obtain age appropriate milestones, especially when they realize the difference and delays that exist between their child and other healthy children” (George, et al., 2007, p.230). Many researchers have used or extended this concept to study parents’ grief reactions.

These two models or theories, while making contributions to the understanding of grief, have also been criticized. The most substantial objections to stage models is that they are an oversimplification. Not all parents go through the stages identified or reach the desired final stage, resulting in families feeling as though they are not grieving the right way and professionals labeling families as dysfunction or pathological (Gilbert, 2007). Another criticism is that the concept of acceptance, resolution or recovery is poorly defined (Gilbert, 2007; Keanery & Griffin, 2001). The basic criticism of the

chronic sorrow model is the inherent negativity of the concept and the lack of distinction between the intensity of the emotions. Findings can be very dependent upon which theoretical perspective the researcher conducting the study seeks to explain. Also some parents may be better at articulating a particular theory or one that has been proposed to them (Seligman & Darling, 2007). Keanery and Griffin (2001) concluded that parents found grief to be confusing, disorderly, unlikely to be neatly resolved, and the notion of acceptance to be confusing. In their study, parents did relate to the concept of chronic or periodic sorrow as a part of their experiences. In Foley's (2006) study, families were found to have a "sustained remission" from grief and were in what he termed a "maintenance" stage, suggesting that chronic sorrow is not a reality for parents. Marlborough and Johnson (2005) found that families do not go through stages in any particular order, they believe that family responses are so varied that it is impossible for a theory to describe the grieving process for all families. Mary (1990) found that 25% of African-American mothers of children with disabilities described a stage like progression through their grief, compared to 68% Caucasian mothers, and 75% Latino mothers.

These models have dominated the perspectives and practices of many health care workers and service providers (Kearney & Griffin, 2001; Woolfson, 2004). Kearney and Griffin (2001) warn, "uncritical application of these theories in the interpretation of the behaviour of parents of children with disabilities has negative implications" (583). Ferguson (2002) conducted a review of the literature in which he identified four evolving professional views of parental responsiveness to disabilities: (1) neurotic parent, (2) suffering parent, (3) powerless parent, and (4) adaptive parent. All but one carries a negative connotation and has influenced the way professionals interact with parents when

disclosing their child's diagnosis and counseling families (Ferguson, 2002; Hasnat & Graves 2000; Proctor, 2004; Sloper & Turner, 1993).

The third theory or concept that has emerged in the disability related grief literature is one that acknowledges that parents may feel positive emotions at the same time as they grieve. Researchers have explained this concept in different ways. Powers (1993) explains that individual parents may report or demonstrate a clear oscillating pattern of responses termed the "peaks and valleys" of grief. Larson (1998) proposes that the grief process is filled with contradictions: she terms them "paradoxes" (p. 871); Trute, Hiebert-Murphy, & Levine (2007) call them "negative and positive appraisal" (p. 7); Kearney and Griffin (2001) term them "between joy and sorrow" (p. 582). These authors explain that while parents' stories are filled with sorrow and pain there is also a great deal of joy that arises out of the search for meaning. Similarly to the concept of chronic sorrow, grief may be felt at recurring moments or specific occasions and perhaps is felt most intensely at the time of the diagnosis (George et al., 2006; Holland, 1996; Lewis, 2003; Powers, 1993; Seligman & Darling, 2007). But in contrast to the other theoretical models, parents expression of joy and hope is not indicative of denial, a lack of acceptance or non resolution.

Processing Grief

A great deal of literature also contributes to the understanding of the ways individuals process their grief reaction. When considering the grief process' elements such as the duration of grief (too long or too short), the intensity of the symptoms (too much or too little), the presence of a physical or psychiatric illness, and the changes in social functioning have been examined (Hansson, et al., 1993). In terms of duration, the

literature indicates that the timeline for bereavement related grief is at least one to three years. The typical time course for disability-related grief is not well understood. Theories related to that of “chronic sorrow” indicate that there may be recurring periods of grief, especially in times of transitions (Foley, 2006). Some argue that subsequent emotional responses may be unrelated to the original grief event and may in fact be part of the everyday stress related to coping with a child with a disability. Parents may not recollect or relive the same intensity of sadness they felt when their child was first diagnosed. Godress, Ozgul, Owen, & Foley-Evan (2004) study found that families of children with a disability experience heightened grief in the first year post diagnosis, followed by a reduction in grief over time. They found that when the initial grief reaction was processed, any recurring episodes of grief were less intense and more manageable over time. Other studies have found that there is no relationship between overcoming grief and the time that had elapsed since the diagnosis, indicating that time alone is not enough (Marvin & Pianata, 1996; Pianta, Marvin, Britner, & Borowitz, 1996). The intensity of the grief reaction, the notion of when normal grief becomes abnormal grief or depression has also been explored, with no clear consensus obtained (Middleton, Raphael, Martinek, & Misso, 1993). Worden (2002) used the term “complicated grief” and identified a set of criteria for identifying complicated bereavement related grief. Some of the indicators include: the inability to speak of the deceased without experiencing fresh and intense grief; the triggering of an intense grief reaction by minor events, the preoccupation with discussion of the loss and the exclusion of loved ones from their lives. Horowitz and colleagues explain that a person who experiences “abnormal” grief “is overwhelmed, resorts to maladaptive behavior, or remains interminably in the state of grief without

progression of the mourning process toward assimilation or accommodation" (Horowitz, Wilner, Marmar, & Krupnick, 1980, p. 1157). Powers (1993) suggests four broad strategies to assist in the determination of whether or not disability-related grief is "dysfunctional". The first is the family member's own assessment of their grief distress and ability to manage the demands of life. The second strategy is to observe, from parental reports, whether there has been a shift in the grief response and the third involves parents reporting whether there has been a lessening of intensity of grief overtime. The fourth strategy is to determine whether a severe psychological disability, such as depression, is present (Powers, 1993).

Differing theoretical frameworks have contributed terms such as "acceptance", "resolution and non-resolution" and "coping" to impart insights into the overall experience of grief. Coping, or using a strategy in the face of stressful situations has been separated into two main types: one is based on how emotions are dealt with and the other at how families problem solve. Problem solving involves information gathering, learning, interacting and deciding. Emotional strategies include hoping, preparing and connecting with others. Based on the work on Dunst and Trivette (1986, 1988), Kandel and Merrick (2007) outlined four characteristics of acceptance: 1) having a reasonable perception of child's skills, weaknesses and limitations, 2) having a realistic view of the child with an appreciation of the complications created in the family, not being overwhelmed by guilt and self pity, 3) being engaged in a logical search for services and not a magical solution, and 4) being able to love the child without feelings of overprotection and rejection not at the expense of all others in the family. Marvin and Pianta (1996) also developed a tool to determine whether or

not parents were “resolved” in terms of their child’s diagnosis. Similar to Powers (1993), Marvin and Pianta (1996) explain that resolution occurs when families demonstrate: 1) a recognition of change since the diagnosis, 2) an assertion of moving on in life, 3) a suspension of the search for a reason the child has the disability or illness, 4) an accurate representation of the child’s abilities, and 5) a balance of statements regarding the benefits of having a child with this disability or illness (Pianta & Marvin, 1996). Families who are still experiencing grief demonstrate 1) cognitive distortions regarding the child’s condition or abilities, 2) an active search for reasons the child has the disability or illness, 3) an inability to move from the past (i.e. actively grieving or overcome with anger, as if the event just happened), 4) a feeling of being emotionally cut off from the experience of the diagnosis, and 5) confusion and mental disorganization (Pianta & Marvin, 1996). Pianta and Marvin (1996) did acknowledge that parents’ representations of their grief process contain elements of both resolution and non resolution. Those researchers who view grief through the joy-sorrow theoretical lens describe parents’ grief process as an embrace of paradox, wherein parents move toward a place of hopefulness by balancing simultaneously their own desires for their child, the oftentimes negative predictions of professionals and their own fears (Kearney & Griffin, 2001; Larson, 1998; Powers, 1993). Powers explains over time there can be a shift in hope, from wishing the disability would go away to wishing that their children would one day live independently. This may be a good indicator of families’ adjustment to the disability.

The various factors that influence grief, grief theories and the processes involved in working through grief provide valuable insights to professionals who are working

with families whose children have been diagnosed with a disability. One briefly touched upon characteristic that is influential in how grief is experienced is support and parents' perception of the support they received (Pianta et al., 1996, Sloman, Springer, & Vachon, 1993; Sen & Yurtsever, 2007). For this reason, professionals need to be aware of disability related grief theories: how they influence their own beliefs about disability and how that, in turn, might influence parents' reactions. Sheeran, Marvin and Pianta (1997) conducted a study wherein mothers with resolved and unresolved feelings of grief did not differ in their need for social support. In their perception of support received the resolved group reported their support system to be more helpful than the unresolved group. Another factor discussed in the literature is access to information, open honest communication and emotional expressiveness between families and professionals (Friehe, et al., 2003; Linblad, Rasmussen, & Sandman, 2005b; Powers, 1993). Kearney and Griffin (2001) have suggested that much of the extended grief experiences of parents are provoked by messages of hopelessness, negative societal attitudes and negative professional beliefs which imply that disability is a tragedy. They concluded by stating that, "practitioners could assist parents in a search for meaning rather than ascribing pathological grief" (p. 588).

The remainder of this chapter will examine the literature on parents' grief reaction in relation to the diagnosis of their child's hearing loss and what elements have been identified as influential about how their grief is processed.

Reaction to the Diagnosis of a Hearing Loss

The diagnosis of hearing loss has many of the same implications for disability-related grief as does the diagnosis of other disabilities. However, some unique experiences contribute to grief as a result of hearing loss. The diagnosis of an infant's hearing loss can have a significant impact on families; 90% of infants born with a hearing loss are born to hearing parents (Northern & Downs, 1991; Wood Jackson & Turnbull, 2004)). Many hearing parents react to the diagnosis of hearing loss with emotions of “grief, shock, anxiety, anger, depression, guilt, resentment, vulnerability, confusion, and panic” (Poon, 1999, p. 17). In 25% of cases, the cause of a hearing loss is unknown and in the 50 % of cases where the cause is genetic, families are often unaware of a family history of hearing loss (Clark, Earls, & McCollum, 2004). Many families have had no prior experience with deafness and consequently are uncertain about its implications (Feher-Pout, 1996; Kutzer-White & Luterman, 2003; Vacarri & Marshark, 1999). Parents have indicated that one of their most significant struggles at the time of diagnosis is coping with the emotions surrounding the diagnosis. These continue throughout the child's development (Roush & Harrison, 2002)

Like other disability-related grief literature, studies applying systems theory to parents' ability to adjust to the diagnosis of their child's hearing loss have attempted to determine which factors influence the impact of hearing loss on family functioning (Feher-Prout, 1996). These variables include: the parents' hearing status, the infant's ability to communicate effectively and any disabilities present in addition to hearing loss (Feher-Prout, 1996; Hintermair, 2006; Mapp & Hudson, 1997; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002). Many researchers have found that the child's degree of hearing

loss does not appear to mediate how parents respond (Hintemair, 2000; Pipp-Siegel et al., 2002). Others have sought study the specific reaction of parents whose children have severe to profound hearing loss, because it is with this degree of hearing loss, that some authors have found parental expectations of development are not met. Therefore communication with the infant is more challenging (Brown, Bakar, Richards & Griffin, 2006). Parental income and education levels, and modes of communication have been found to be insignificant predictors of parental stress (Calderon & Greenberg, 1999; Hintemair, 2006; Lederberg & Golbach, 2001; Pipp-Siegel et al., 2002). External variables such as social and personal support have been influential to parental adjustment (Calderon & Greenberg, 1999; Lederberg & Golbach, 2001; Mapp & Hudson, 1997; Pipp-Siegel et al., 2002; Quittner, Glueckauf, & Jackson, 1990).

EHDI programs have provided opportunities for new research in the field because of the “changed circumstances” (Young & Tattersall, 2007, p.210); a medically driven discovery mechanism, a highly compressed timescale between birth and diagnosis, the diagnosis occurring at the earliest stage of relationship formation, and early intervention occurring quickly and intensely in the child’s life (Young & Tattersall, 2007). New studies have begun to look at whether the grief reaction changed and whether and how professionals supported and counseled grieving parents. Concerns have been raised that a newborn diagnosis negatively impacts parent-child bonding during a vulnerable and critical time (Kutzer-White & Luterman, 2003). Other studies have suggested that early identification benefits both the parent and child by allowing for quicker resolution of grief, improved bonding, and decreased parental stress (Yoshinaga-Itano, 2001; 2003). The evidence from these conclusions is not yet well established (Tattersall & Young,

2006). The following section will review literature documenting parents whose children have been diagnosed with a hearing loss prior to EHDI programs and as a result of EHDI programs. It will explore research pertaining to the ways in which professionals have supported parents through their grief.

Evidence for the Existence of Grief

McKinnon, Moran and Pederson (2004) explained that Kubler Ross' model of the grief reaction has been commonly applied to parents' reaction to the diagnosis of their children's hearing loss. Luterman (2001) has equated parents' reaction to learning about their child's hearing loss to the loss of the hoped for future, child and life that the family had anticipated. Kurtzer-White and Luterman (2003) have also stated that the parental reaction to the diagnosis of hearing loss is closely related to chronic sorrow, where parents not only experience grief at the time of the diagnosis but thereafter throughout the lifespan of the child. Triggering events for these feelings of grief include: the lateness of first words; the noticeable difference between hearing peers and their child; especially their child's inability to fully socialize with hearing peers. Follow up audiological appointment and periods of transitions are also triggers. In qualitative studies of parents' perspectives on the EHDI programs, parents have shared their grief reactions surrounding the diagnosis of their child's hearing loss. Anagnostou, Graham, and Crocker's (2007) study of parental emotions following the diagnosis reported that grief is one of the strongest feelings after the diagnosis. As reported, the grief reaction is associated with a lack of acceptance about the child's hearing loss and a continued search for cures. Retrospectively, parents have described their initial reactions by stating,

It's like a death; it's really like a death. [Your child] is still alive, of course, but to have some of your hopes crushed ... with that comes the experience of loss, and with that comes the experience of grieving" (Kelly & Bibby, 2008, p.96).

The grief that has been described in the context of EHDI concerns the diagnosis at the newborn stage; the diagnostic process itself; the developmental outcomes associated with hearing loss, and the decision making process that parents inevitably encounter. Each of these areas will be discussed within the context of grieving.

Newborn diagnosis.

The newborn period represents a vulnerable time when "mothers are recovering from birth" and some researchers have suggested that if parents are told about their child's hearing loss at that point it will cause more grief than if the diagnosis occurs later (Kutzer-White & Luterman, 2003, p. 233). Another concern was that families are learning about their child's hearing loss before they have been able to develop their own observations which may give families needed time to prepare for the diagnosis (Luterman & Kutzer-White, 1999; Vohr, Letourneau, & McDermott, 2001). Young and Tattersall (2007) explain that within the context of EHDI programs, parents are in the difficult position of trying to balance the grief that results from the knowledge of their child's hearing loss with the advantage that knowing early allows them. Their study observed that for some families, an early diagnosis was positive giving them a sense of time to get used to the hearing loss, to make plans and to prepare. For others families it created pressure, which is further discussed in the section on decision making. Fitzpatrick and colleagues (2007) conducted a study wherein some families, from groups with children both screened at birth and not screened at birth, expressed that they did not feel the urgency to have their child's hearing loss diagnosed at birth. Rather they would have

liked to have had the opportunity to know their baby without being “sorry and frustrated” (Fitzpatrick, Graham, Durieux-Smith, Angus & Coyle, 2007, p 101). Yoshinaga-Itano (2001) reported on an unpublished study conducted by Pipp-Seigel (2000) on the resolution of grief in families whose infants were diagnosed with a hearing loss. The study was conducted with 16 families, 10 were resolved and 6 were unresolved regarding their grief surrounding their infant’s diagnosis. Families who were resolved had infants identified, on average, approximately 8 months earlier than those families who remained unresolved. Young and Tattersall (2007) challenged those findings stating that it is not clear whether it is the early identification or improved language outcomes that created the differences in this study.

Diagnostic process.

Yoshinaga-Itano (2000) explained that there are four unhelpful ways of providing information to families regarding the diagnosis of their child’s hearing loss. These are: the “hit and run approach” factual, bleak and to the point; the “action-orientated approach” a listing of tasks that parents must complete; “the objectivity approach” medical and filled with jargon, and the “minimizing the problem approach”, intended to take the pain away. While professionals have gained greater knowledge about ways to impart diagnosis, parents perceptions continued to reflect some negative experiences with professionals (Hall, 1996; Taanila, Jarvelin, & Kokkonen, 1998). Parents have reported feeling as if they did not receive enough help nor enough opportunities to ask questions (Taanila et al., 1998). Graungaard and Skov (2006) explained that in their study, professionals underestimated parents’ emotional distress and need for information. One of the purposes of the implementation of EHDI programs has been to streamline the

diagnostic process but parents continue to share experiences of others contributing to their feelings of grief (Seligman & Darling, 2007; Park, Warner, Sturgill, & Alder, 2006). Parents have expressed feeling hurt and upset when, after learning of their child's hearing loss, they are treated in a manner that they deem insensitive (Corcoran, Stewart, Glynn, & Woodman, 2000). Robinshaw and Evans' (2003) study found parents were outraged by the way they were informed about the child's hearing loss as they reported being told,

in corridors, without any preparation, when their spouse had just left the room, without reference to any follow up support and with other professionals watching passively as the parent tried to distract the over tired, attention seeking infant and toddler whilst she tried to understand and retain what was being said (p. 15).

In Park and colleague's (2006) study, parents reported experiencing difficulties and delays when it came to trying to obtain an appointment with a pediatric audiologist and to obtain a referral from the primary care physician. They also reported difficulties associated with undergoing multiple tests before the diagnosis, the presence of middle ear fluid, and poor medical advice. Parents of children diagnosed with a hearing loss have reported feeling as though audiologists were unaware of the grief they experienced upon receiving the diagnosis. They also reported feeling as though audiologists were not supportive once when they initially learned about their child's hearing loss (Roush, 2000). Parents' expressed the desire to be informed about their child's hearing loss "by an audiologist who is not only a skilled clinician but also an empathetic, supportive counsellor" (Luterman & Kutzer-White, 1999, p. 16). Tattersall and Young (2006) conducted a study examining parents' reactions to the diagnostic process and found parents felt as though their encounters with professionals were marked by poor explanations, insensitivity, a lack of partnerships and honesty (Tattersall & Young,

2006). Young (1999) found that the model of deafness that professionals ascribe to also influences parents' adjustment to their infant's diagnosis. Other qualitative studies have found that parents often fail to understand the language used by professionals. Russ, Kuo, Poulakis, Barker, Rickards, Sauders, et al., (2004) identified that parents often report communication difficulties and misunderstanding with the professionals that they work with in EHDI programs. In their study, parents explained that the professionals were giving very complex information at a time when they were unable to absorb it.

Outcomes of hearing loss.

After parents received the diagnosis many had questions regarding their child's hearing loss, overall development, and especially language development. Pain (1999) found that parents of a child with a disability indicated a need for information to enhance the management of their child, to cope emotionally with the situation and to be able to access services and benefits. Fitzpatrick, Angus, Durieux-Smith, Graham and Coyle's (2008) study of infants identified with a hearing loss found that parents' need for information regarding their child's prognosis for oral language development coincided with the lack of such information. These authors pointed out that the literature is unclear as to whether or not this is as a result of providers being unaware of parents' needs for this type of information, providers being uncomfortable providing such information or because of a lack of evidence based indicators for the provision of such information (Fitzpatrick et al., 2008). Other researchers have indicated that in terms of a child's prognosis, professionals can only respond with unpredictability and uncertainty (Kutzer-White & Luterman, 1999). Sloman, Springer and Vachon (1993) explain that the impact that hearing loss has on a child's ability to develop spoken language is not always clear

making it difficult to offer predictions about how well a child will learn to speak. The latter is a common concern among hearing parents. Unpredictability and uncertainty are factors known to impact the grief reaction of parents of children with a disability (Hilton, 1993). While some parents experience unpredictability and uncertainty; many turn to professionals with hope, seeking guarantees that their child will develop spoken communication. They often base intervention decisions on these guarantees (Sloman, Springer, Vachon, 1993). Young and Tattersal (2007) warn of the “the potent promise of normalization”, that with a particular kind of intervention, a child will become just like a child with typical hearing. While in many cases children with hearing loss are able to develop spoken language on par with their hearing peers, many do not. For those parents, the grief experience may be affected as a result of their clinging to unachievable goals or their hoping for therapies and technologies that will fix their child’s hearing loss. Parents may suspend, mask or disallow themselves to grieve while they wait to see how their child’s language will develop. Potentially this could result in parents not processing their emotions and integrating the realities of their life with what they had expected upon the birth of their child (Anagnostou et al., 2007; Sloman, Springer, & Vachon, 1993). Not only does this impact the time immediately following the diagnosis but as Young and Tattersall (2007) explain,

Parents feel betrayed later on in their children’s lives when the possibilities they were originally offered for their child’s development fail to be realized, particularly in cases where oral development trajectories were pursued to the exclusion of all others (p. 218).

Howe (2006) also explains that when, “a disability affects communication,” as hearing loss does, parents have “problems in how to interpret needs and behaviours” (p. 99)

which may make them less responsive in their caregiving. This shortfall potentially influences grief over the long term.

Decision making.

Young, et al., (2005) state, “making difficult choices is one of the enduring and repeated experiences of being a parent with a deaf child” (p.67). What is most often discussed in the context of decision making and hearing loss is the communication decisions that parents are asked to make. Parents often report being presented with challenging technical information, a range of “bewildering” options, a range of professionals with differing and complex information, as well as differing perspectives about early intervention. All of these experiences can create distress in families (Feher-Pout, 1996; Kurtzer-White & Luterman, 2003; Young, Hunt, Carr, Hall, McCracken, & Tattersall, 2005). Parents have also expressed feeling as though they had little time to really investigate their options before making an intervention choice (Fitzpatrick et al., 2007). Parent perspective literature has also indicated that parents reported feeling as though professionals did not make them fully aware of the range of choices available (Young, Carr, Hunt, McCracken, Skipp, Tattersall, 2006).

The grief reaction is capable of influencing decision making (Young & Tattersall, 2007; Mindel & Vernon, 1974; Steinberg & Bain, 2001). Steinberg and Bain (2001) explain that a perceived time pressure,

effects judgment by altering risk taking propensities, increasing the importance of internal rather than external sources of information and induces change in the underlying cognitive processes including filtration, omission, and attribute based processing of available information (p.4).

They go on to state that time pressures are not always negative if individuals have the resources to meet the challenge, but if they do not, as is the case for many hearing parents whose newborn is diagnosed with a hearing loss, negative emotional states may result (Steinberg & Bain, 2001).

While the goal of EHDI programs is to have infants enrolled in early intervention by 6 months, there is little research indicating that parents do or do not feel a time pressure in the context of those programs. Kutzer-White and Luterman (2003) reported that only 15% of children identified through EHDI programs enroll in an intervention program before 6 months. Further investigation is required to determine whether this inaction is related parental grief, the amount of support received or other individual family factors.

Supporting Families through their Grief

This following section will focus on the literature pertaining to the provision of formal support for families of children with disabilities, specifically professional support for families of children who were diagnosed with a hearing loss in EHDI programs. Professional support is discussed from the perspective of parents receiving the service, professionals providing it and researchers studying it. Various labels are ascribed to professionals who provide support services to families of children with disabilities: family support workers, social workers, nurses, link workers, health care coordinators, key workers, and link family support persons (King & Myers, 2006; Sloper, 1999). Support has been described as occurring in the form of discussions, information, time spent listening, helping, and counseling and responding to immediate needs, developing parental confidence and working with other professionals (Hall, 1996; Mitchell & Sloper,

2001; Sarajarvi, Haapmaki, and Paavilainen, 2006). Topics have focused on improvements to the provision of family centered care, the facilitation of coordination, the engagement in good informational practices, and the provision of appropriate emotional support (Linblad, Rasmussen, & Sandman, 2005a). Professionals in support positions differ in terms of the qualifications and specific roles or responsibilities (Greco, Sloper, Weeb & Beecham, 2006; King & Myers, 2006). Rahi, Manaras, Tuomainen and Hundt's (2004) study of the implementation of a support professional into a health program found that they had a direct effect on: parents feeling emotionally supported at the time of the diagnosis, parents' perception of an increase in information provision, including the opportunity to make contact with other parent support groups, and liaison with specific referral to services. But presence alone of a support worker does not guarantee a positive experience of support for parents. Some studies have found that parents are dissatisfied with the way they are supported by professionals, when they first learn of their child's disability even in the presence of support worker services (Fitzpatrick et al., 2008; Hall, 1996; Graungaard & Skov, 2006; Taanila, et al., 1998). Parents have identified important qualities or characteristics that a support worker should possess. Demonstration of a genuine interest in the wellbeing of the infants of the families they support has been identified as an important quality (King & Meyers, 2006; Sarajarvi, et al., 2006). Linblad, Rasmussen and Sandman (2005a) interviewed professionals nominated by families as examples of "good supporters" to find out the meaning that professionals attributed to that term. They defined being a good supporter as having "hope and conviction that something can always be done to improve the situation

for a child and his or her family” (p. 217), being trustworthy, and having confidence in the parents.

Many EHDI programs have developed a specialized position for a professional support worker to address the specific needs of families with infants diagnosed with a hearing loss (Hyde, 2005). In many cases, these professionals are specialists in hearing loss and in their province/states early intervention system. They represent a single point of entry into the deaf and hard of hearings service delivery system (Stredler-Brown, 2004). The literature has described some of their responsibilities as counseling, educating, and guiding the family after the diagnosis of their child’s hearing loss. Support workers can provide information pertaining to program options, can describe and can demonstrate various communication options, can inform families about resources, funding sources, and consent for information sharing (Brown, & MacKenzie, 2005; Stredler-Brown, 2004). Research addressing how families in EHDI programs have experienced professional support from these individuals is beginning to emerge. A recent study by Fitzpatrick et al. (2008) found that parents had varying views on the need and value of family support workers. Even though parents were provided with social support services after their newborn was diagnosed with a hearing loss, parents were frustrated because they felt as though the professionals did not know enough about the technical aspects of hearing loss. While research has acknowledged that this is a very sensitive and vulnerable time for parents and that support can be essential at this time, there is still a gap and a need for further research regarding best practice and the reality of parents’ experiences (Rush, Shelden, & Hanft, 2003).

Informational support.

The need for information occurs at various points throughout the time when parents make meaning of their child's diagnosis. Parents need information when they first receive their child's diagnosis and as they make decisions regarding intervention. The amount of information, the way in which it is delivered and the perceived understanding of parents' concerns are significant variables influencing how parents feel about the way in which they were informed about their child's diagnosis (Hasnat and Graves, 2000). A number of studies address models or best practices for disclosing a disability to parents that have led to higher levels of parental satisfaction. Sloper and Turner (1993) explained that it is best if both parents can be in the room when the professional provides the diagnosis and it should be done in a sensitive and honest manner. Some studies also recommend that professionals assess each individual family and tailor the information that they deliver to what they feel will meet the families' needs (Sloper & Turner, 1993). Others warn of this behaviour as it could be seen as "professional paternalism – an attitude that controls what parents are allowed to know" (Tattersall & Young, 2006, p. 37). Boyd (2001) recommends that information be provided in as many forms as possible: pamphlets, booklets, books, follow-up letters, and/or telephone calls. Some literature also talks about the need to strike a balance between hopeful and positive information and the fact that reality can sometimes be different (Young et al., 2005). Pain (1999) explains that the provision of information is greatly enhanced when programs have support workers. Taanila and colleagues (1998) recommend that parents should have access to a support worker early and that the initial

situation would be improved if the support worker were present at the time of disclosure of the disability to help create a safe atmosphere for families.

Parents also need informational support as they seek to acquire the knowledge that they need in order to make the many decisions on behalf of their child hearing loss. Those decisions centre mainly on communication and intervention programming. The role of the support worker has been identified to ensure that parents are provided with comprehensive, meaningful, unbiased and relevant information (Young et al., 2006). Young, Carr, Hunt, McCracken, Skipp and Tattersall (2006) explored the concept of informed choice and have expertly articulated their view of the challenges involved in applying the concept of informed choice to the field of deafness. Providing accurate information on language and social outcomes can be difficult as there is still limited “good evidence base for the effectiveness of some of the most basic interventions which [professionals] routinely ask parents to make decisions about” (Young et al., 2006). Therefore the challenge in this context the provision of evaluative information that demonstrates uncertainty and helps parents contend with this fact.

Good informational support is also said to be provided when parents are encouraged to make decisions at their own pace, to talk to other parents and to be alerted to the fact that other parents and professionals may have their own agendas. For parents to profit from any of this professional advice, they must know how to use the information (Young et al, 2005). Another identified challenge is that professionals in deaf and hard of hearing early intervention programs often provide high quality information about the choice that is available to families within their program but feel as though it is not their place to provide information regarding other options. This can be challenging for parents

who are easily influenced and impressionable, and who are still acquiring knowledge (Young et al, 2006). Young, et al., (2005) remarked that often even with equal information regarding all possible options, it can still be difficult for families to make an informed decision.

Counseling and emotional support.

Yoshinaga-Itano (2001) stated that with immediate support provided by a professional with appropriate counseling skills and expert knowledge about hearing loss, the resolution of grief can occur more quickly. Appropriate counseling skills involve many different elements. Lynch and Morley (1995) state that understanding grief processes provides the basics for developing counseling intervention with families. Acknowledging parents' feelings where they are is another important aspect of being a good counselor involves (English, 2007). The relationship with families' should begin with the professional ready to listen and acknowledge families' immediate concerns and needs (Gloeckler & Proctor, 2004). Luterman (2006) explains that people, who are in pain, need to be listened to and to have their feelings validated which can be counter-intuitive to some counselors who want to take the pain away. When professionals make reassuring blanket statements, it can result in parents feeling as if their concerns are being denied, and that their anxieties should not exist, making them, in fact, feel worse (English, 2007). Professionals need to develop their own self-awareness and understand their own strengths and biases. By becoming more self-aware, professionals can recognize their communication patterns, values, beliefs, needs, and interpersonal skills and determine how to work within them ensuring that they do not negatively affect individual families (Rosin, Whitehead, Tuchman, Jesien, Begun, & Irwin, 1996).

Professionals should also strive to build a rapport with families through empathy, warmth, sensitivity, and unconditional positive regard (English, 2007). Unconditional positive regard towards the family conveys confidence which further assists them in decision making and advocacy for their child (Gloeckler & Proctor, 2004).

Understanding each family's individuality and uniqueness could also help professionals assist families to identify their own strengths (Benedict & Raimondo, 2003). Lynch and Morley (1995) also indicated that group counseling could be very beneficial for parents of children with a disability. Parents can help support one another in order to decrease their feelings of isolation and stress. Parents may withdraw from their support networks or alternatively some may feel their support networks pull away, unsure of how to provide appropriate support (Featherstone, 1981).

In many programs servicing families of children with disabilities, professional support workers are obligated to balance the provision of both emotional and informational support. To provide emotional support, the professional must set aside their informational agenda and listen. Professionals cannot express any point of view, other than to hear and understand the families' concerns. Professionals need to be able to differentiate a teaching moment from a counseling moment, yet be capable of moving seamlessly between both (Luterman, 2006). Some parents may not expect the professionals that they encounter in that setting to talk with them about their feelings, either because they do not perceive it as the professional's role or because they feel that needing/using support is a measure of failure or vulnerability (Luterman, 2006). Parents therefore need to be invited to share their feelings with the professional.

While there is much discussion in the literature on the pervasive negative focus on parental reactions to a child's disability (Kearney & Griffin, 2001), there continues to be some acknowledgment of the value of validating the grief reactions that some parents may experience, as well as researching how professionals can facilitate and enable the processing of those feelings. With this knowledge, professionals can assist parents in shifting their perspective to focus on the positive (Ferguson, 2002; Powers, 1993). The diagnosis of a child's hearing loss in the context of EHDI programs necessitates some unique considerations, not only for the grief process, but also for the ways in which professionals can support families. Not only is it important to understand the grief process but also to know how families are able to process their grief and to know what elements of professional support assist in that processing.

The purpose of this study was twofold: firstly, to explore parents' reaction to the diagnosis of their child's hearing loss in the context of EHDI programs, specifically their grief reaction. Secondly, as parents transition to early intervention what emotional and informational support do they perceive as beneficial to their journey. Specifically the research questions are:

- 1) How do parents of children who are diagnosed with a hearing loss in the context of an EHDI program experience grief?
- 2) What professional support factors assist parents in processing their grief?
- 3) Is decision making impacted by the grief that some families experience and/or the support offered by professionals?
- 4) Do the mothers' and fathers' perceptions and needs differ?

These four research questions will be investigated through a phenomenological approach. The next chapter provides further information regarding the methodology.

Chapter 3- Methods

This qualitative study utilized a phenomenological research design to assist in the understanding of the meaning that participants assigned to their grief experience and their perceptions about emotional support upon learning of their child's hearing loss through an early Hearing Detection and Intervention (EHDI) program. The purpose of phenomenological research is to illuminate a phenomenon through the perspectives of a participants lived experience (Groenewald, 2004; Kvale, 1996; Lester, 1999). This illumination occurs through the collection of in-depth information, achieved through qualitative methods such as interviewing, focus groups and /or observations. Through interpretation of that shared meaning, a "vivid", "rich in detail and context" understanding of a particular phenomenon can be achieved (Sorrell & Redmond, 1994). While there are many variations in phenomenological studies, Giorgi (1989) identified core phenomenological characteristics: that the research is descriptive, that it investigates the relationships between participants and situations and builds meaning of human experiences. This design was chosen for this study as it permitted participants to become engaged in an open and deep discussion about their grief adjustment to their child's hearing loss from their own perspective. Research has also stated that a phenomenological approach is well suited for sensitive topics (Donalek, 2004; Tattersal & Young, 2006). The use of this research design was also suitable to the purpose of this study because phenomenological research is particularly effective in challenging existing assumptions and addressing gaps between knowledge and reality (Lester, 1999). The interpretation of the personal perspectives permits insights to be drawn that have the potential to influence policy and practices.

Phenomenological research also acknowledges “the importance of making clear how interpretations and meanings have been placed on the findings, as well as making the researcher visible in the ‘frame’ of the research” (Lester, 1999; Wertz, 2005).

Phenomenological research acknowledges that the researcher cannot be detached from her own beliefs and assumptions (Hammersley, 2000; Koch & Harrington, 1998).

Therefore it is important for the researcher to engage in reflexivity (Creswell, 2005).

Creswell (2005) defines reflexivity as the researcher’s ability to be aware of her role in a way that honors the perspectives of participants. In order to be aware of one’s role in the phenomenological research process, the researcher must acknowledge how her own history, background and preconceptions influenced the data collection and final interpretations.

Role of the researcher

The researcher of this study has professional and academic experience that she brings to this work. A master’s degree in educational psychology, in the area of deafness studies, provided her the opportunity to conduct previous research in the field of parents’ experiences in the context of an early hearing detection and intervention program. This training also prepared her to work as an interventionist with deaf and hard of hearing children. The researcher has also had professional work experience as a Family Support Worker to families whose children are newly diagnosed with hearing loss. These experiences have shaped the researchers understanding and preconceptions in a number of ways. As previously stated, the impetus for this present study is a result of literature indicating that parental grief is felt less when a diagnosis occurs at a child’s initial stages of development. The researcher’s experience working in a province where there is no

universal newborn hearing screening and conducting previous research with families whose children were diagnosed at birth, caused her to question the validity of such claims. Also wanting to better understand how to support families through this process provided another motivation for this research. Her experiences also contributed to her preconception that often parents turn to professionals for direction about what intervention they should pursue. And that sometimes professionals can forget the immense impact that they have on parents, and their processing of emotions and decision making. In terms of data collection it was important for the researcher to keep at the forefront of her mind that she was there in her role as researcher, not family supporter, not information provider or early interventionist. Remaining in the role of a researcher, an astute listener, was necessary to achieve the important purpose of understanding the meaning made by the parents of their experiences. During data analysis it was also important to acknowledge that the researcher may have been more sensitive to various statements because of the personal understandings she brought to the study. For example, due to the researcher's belief that parents whose children are diagnosed with hearing loss at birth may not have a reduced grief experience, she was aware of indirect and conflicting expressions of grief. In order to ensure that the researcher was honest to the participants' constructed meaning of the phenomenon, the researcher engaged in a continuous dialogue with her advisor in order to remain consciously aware of her own preconceptions (Hycner, 1989). Validity is demonstrated when the researchers are clear about how they have influenced each part of data analysis, why was a topic chosen, and why responses were drawn in a particular way (Drew, 2001)

Locating the Research and Research Participants

It was important that this research take place in a Canadian province with an implemented EHDI program. Canadian programs differ from province to province; the few Canadian provinces that have comprehensive EHDI programs could serve as models for those provinces that have none. Parent participants were recruited from Ontario's EHDI program, called the Infant Hearing Program (IHP), Canada's more mature program, implemented in 2002. The benchmarks for this program include the need to have all newborn infants screened by the age of 1 month, diagnosed by three months and enrolled in an intervention program by six months. Family support is a component of the overall program. All families in Ontario are provided with the opportunity to access a Family Support Worker (FSW) who is a regulated health professional who "counsels, educates and guides the family" (Brown & MacKenzie, 2005, p. 10). The Ontario IHP is broken up into a number of different regions. The outline of the study was explained via email sent to a region covering a larger urban centre seeking their interest in participation. Program administrators of this region responded promptly and indicated the need for a separate ethics review, which was immediately undertaken. To ensure the desired sample size of 7-10 families, it was felt that other surrounding regions should also be contacted. Surrounding regions were selected based on distance from the urban centre to reduce the travel required by participants and the researcher. Program administrators were contacted from three surrounding regions. Two declined to participate, one due to budget constraints limiting resources and the other due to limited family support coverage for their families. The surrounding region that agreed to participate reviewed and approved the University of Manitoba Ethics application.

Purposeful sampling was undertaken in order to select information-rich research participants (Patton, 2002). Specific criteria were delineated in order to capture a sample that suited the purpose of the research. This was done with the assistance of program managers who manage the regional IHP. A letter was sent to program managers requesting their assistance in selecting and mailing packages to parents who met the inclusion criteria. The criteria for participation were as follows. Firstly, both male and female caregivers were asked to participate in the study if at all possible although involvement would not be excluded if it were not possible. Hearing parent participants were sought since parents who are hard of hearing or Deaf each have their own set of unique experiences that may have influenced the way they experienced the diagnosis. The inclusion of hard of hearing or Deaf parents would result in equally important but different findings and needs compared to those of hearing parents. The infant's hearing loss had to be a permanent sensorineural hearing loss in the moderate to profound range. Specification of the degree of hearing loss was intended to provide some homogeneity in the sample although previous research did not predict that parents' reactions to their diagnosis would necessarily vary according to the severity of their child's hearing loss. The fourth criterion was the time span of at least 6 months but no greater than 4 years elapse from the diagnosis to the time of the interview in order for the discussion to extend beyond the initial grief reaction to an examination of the way grief was processed. For this reason, the sample was limited to parents with children of similar ages and abilities. The parents of school aged children and children with additional medical diagnosis were excluded. The letter to program managers is included as Appendix A.

The packages to parents included a letter specifying that if interested, they should contact the researcher directly either electronically, via mail or the telephone. This ensured that participants' names remained unknown to the program managers. Parents were informed that their program managers would have no way of knowing whether or not they participated, ensuring that their participation would in no way affect the services they received from the IHP. The letter informed parents of the three elements required for their participation: 1) a short informal language assessment of the child, 2) a group discussion among fathers and a group discussion among mothers who have experienced their child's diagnosis with a hearing loss, 3) a short questionnaire following the focus group experience. Participants were asked to commit to an estimated 2 hours and 30 minutes. Parents were also informed that they would be reimbursed for up to \$100 for any expenses they incurred to facilitate their participation in the study (i.e. for childcare services, travel or parking). The parent letter is attached as Appendix B. Before participating in data collection, parents were asked to sign a consent form. The consent form made them aware that they could withdraw from the study at any point, without any negative consequences whatsoever. The consent form is attached in Appendix C. A total of 59 information packages were mailed out. Thirty-two parents were identified and mailed packages in one participating region. Of those, eight families contacted the researcher and six participated in the study. Twenty-seven parents were identified and mailed packages in the second region, three contacted the researcher and two families participated. Those families' who contacted the researcher but did not participate opted out because of busy family and work schedules. The low return rate was expected given the high demand on these families to attend clinical and research appointments.

Description of Participants

The sample of participants for this study consisted of eight hearing families, eight mothers and seven fathers whose children had been diagnosed with a hearing loss through the IHP. Table 1 provides demographic information for each participating family.

Each of the fifteen participants was the biological parent of a child who was diagnosed with hearing loss through the IHP. All families use English in their home and live in an urban setting. All families except for one have a household income of \$85 000 or higher. For five families, their child with the hearing loss is their only child; for two families the child with a hearing loss is their second born; and for one family he is their first born. Children's ages were between 12 months and 3 years, 10 months. The degree of hearing loss ranged from moderate severe to profound. Every child, who was eligible for a cochlear implant, received bilateral implants prior to or by twelve months of age. All of the children were enrolled in Auditory Verbal therapy; two children were also learning signed language.

Table 1.
Participant Demographics

Parent Name	Parent Age Range	Child Name & Current Age	Degree HL	Age at Diagnosis	Income Per Home	Birth Order	Amplification & Age of Amplification	Choice of Intervention Program
Claire & Eric	26-35	Liam, 16 mos	Profound	2 mos	> \$85 thousand	Only child	Bilateral CI at 10 mos	AV, ASL & Oral
Val & James	36-45	Brody, 2 ½ yrs	Profound	3 mos	> \$85 thousand	2 nd	Bilateral CI at 10 mos	AV
Zoe	19-25	Lucas, 18 mos	Profound	2 mos	\$36 000 – 55 000	Only Child	Bilateral CI at 9 mos	AV (Oral)
Elizabeth & Rob	36-45	Wyatt, 28 mos	Severe-Profound	3 mos	\$56 000 – 85 000	Only Child	Hearing Aids	AV, ASL & Oral
Christina & Derek	26-35	Noah, 12 mos	Moderate- -Severe	4 mos	> \$85 thousand	Only Child	Hearing Aids at 6 mos	AV

Julia & Adam	26-35	Parker, 3year 9 mos	Severe- Profound	2-3 mos	> \$85 thousand	1 st	Bilateral CI at 12 mos	AV
Hannah & Jason	36-45	Ella, 25 mos	Profound	2 mos	> \$85 thousand	2 nd	Bilateral CI at 8 months	AV
Rachael & Chris	36-45	Levi, 3 yrs 10 mos	Moderate - Severe	3 mos	> \$85 000	Only Child	Hearing Aids at 6 months	AV

Data Collection

The phenomenological research approach was well suited to data collection because in the search for meaning it allows for an artful combination of listening and narratives (Sorrell & Redmond, 1994). Active listening shapes how the researcher is able to interpret parents' narratives and provides participants an opportunity to "participate in" the interview. Narratives were drawn from participants through the use of focus groups (Sorrell & Redmond, 1994). This method for data collection allowed parents to share the ways in which they want their experiences understood (Tattersall & Young, 2006). The focus groups were guided by questions developed by the researcher and based on relevant literature. The topics were intended to foster discussions that would allow the researcher to gain an in-depth understanding of parents' grief and grief processes. The focus group guide is attached as Appendix D. The following statement from Sorrell and Redmond (1994) highlights the strengths and potential challenge that can be encountered with this data collection style, "The interviewer wants to evoke responses that are natural aspects of the individual respondents experience, rather than have the respondent fit responses to preconceived categories or interpretations. Sometimes the most difficult respondents to interview with this approach are the most educated who may want to fit their responses to already known criteria" (p. 1121).

As phenomenological data is intended to produce a great depth and breadth of knowledge, the establishment of rapport and empathy is of utmost importance to this process (Lester, 1999). A child language observation was also conducted as a means of establishing rapport with families and also to provide the researcher with some context in which to place parents' perception of their child's language development. These

observations occurred before the focus groups and took place most often in the families' homes. Rapport with families was facilitated by the researcher's prior knowledge of the field, genuine interest in the participating children and in her connections with families on topics other than those of the study (i.e. casual conversing with the parents). This was also meant to help put parents more at ease with the researcher, and thereby encouraging more open discussions of the vulnerable focus group topics.

Focus groups.

Bodgan and Biklen (2007) explained that focus groups "are structured to foster talk among the participants about particular issues" (p.109). Focus groups encourage participants to talk to one another, to exchange stories, and to comment on each other's experiences and points of views, therefore allowing themselves to further reflect on their own experiences and points of view (Stewart, Shamdasani, & Rook, 2007). Focus groups were chosen as a means of data collection because the researcher was felt that participants would be more apt to reveal sensitive information when they felt comfortable and safe in an environment with people like themselves. It was felt that this setting would help parents discuss grief. Specially whether the grief experience was shared by all parents, or how it differed at various stages, or for various individuals and across couples (Krueger & Casey, 2003). As the focus group discussion developed, insights from the perceptions of people who shared a similar experience resulted in rich exchanges illuminating the variation of experiences and feelings (Willgerodt, 2003).

The focus groups consisted of two groupings of fathers and three groupings of mothers. The rationale for conducting separate father and mother focus groups was the difference noted and described in the literature, resulting from the diagnosis of a child's

disability between mothers and fathers. By separating spouses the researcher intended to create the opportunity for the individual to share his or her own perspective as opposed to the couples perspective. Scheduling proved to be difficult for the father focus groups; this resulted in one larger focus group of six fathers in one participating region and a focus group of two in the other. Two focus groups involved three mothers in one region and one focus group involved two mothers in the other. All focus groups took place in a quiet and private location where participants could feel relaxed and free to express their true feeling.

While participant narratives shaped the focus group process, it was helpful to provide a guide for participants to keep a specific focus (Sorrell & Redmond, 1994). Patton (2002) also explained that, “the power of the focus group resides in their being focused” (p. 388). This was achieved through the use of a chart outlining the topics to be discussed which was posted in each focus group location. Topics listed were as follow: the parents’ emotional journey, the perception of emotional and informational support, the parents decision making process and the difference in support needs between husband and wives. As parents arrived to the focus group site, they were invited to review the chart and reflect on their experiences before the group discussion began. A small number of topics were selected for discussion because of the emotional intensity of those topics and the necessity for the discussion to not exceed two hours. Lengthier times would exhaust the participants. The opening question invited parents to introduce the group to their child. For each parent this was a jumping off point to vivid narratives regarding the process of coming to learn of their child’s hearing loss. The researcher often posed thoughtful probes asking parents to connect to their feelings and elaborate further around

their described experiences (Sorrell & Redmond, 1994). As each participant shared their stories, described relevant experiences or offered differing opinions, the conversation developed. New topics were introduced when a particular flow of conversation ceased to elicit new discussion.

Child language observation and interaction.

The child language observations served two purposes in the study. The first was to establish rapport with families prior to the commencement of the focus groups. The second purpose was to provide the researcher with some context in which to place any subsequent discussion that might occur around their child's language development. The researcher anticipated that language development would be discussed in the focus groups because language development is often the highest priority for parents of children with hearing loss, specifically spoken language development. There exists the potential that parental emotional well-being may be influenced or tied to perceptions of language development. Therefore understanding parents' perception of language development in general, their perception of their child's language skills and being able to have a sense of their child's actual language skills provided a point of comparison with which insight could be gained as to whether or not their child's language development was influential to their experience of grief or grief process.

The child language observation and interaction was conducted by the researcher in each family's home except for one case where it was done with a parent at the child's daycare. Parents were involved in interactions and when possible both parents were home throughout the observation and interaction. The observations and interactions were play based and occurred most often on play areas or living room floors. Parents were made

aware that there was no formal language testing taking place: that the language assessment was intended not to diagnosis a language delay, but rather to assist the researcher in understanding how the children's language development was progressing. Specific interactions with each child were based on a common North American language assessment, the *Preschool Language Scale, Fourth Edition* (Zimmerman, Steiner, Evatt-Pond, 2002). .This was done to provide the researcher with a standardized normal developmental point of reference in which to place the children's language skills. As the children in the study were all under the age of 4 years, time was spent playing with the test manipulatives and with the children's own toys in an attempt to place the child at ease and to elicit certain language skills. As this test is composed of two subscales: Auditory Comprehension and Expressive Communication; interactions occurred that elicited both receptive and expressive communication. The communication skills being observed were naturally elicited as the items in the communication scales include basic communication concepts such as turn taking, labeling, and following simple directions. These activities were incorporated into the general interaction and play with the children. The researcher has training at the graduate level as an early interventionist for deaf and hard of hearing children and has worked in that role for five years. She had previous experience using the test and received training for its administration by a speech language pathologist. Spoken language was the main mode of communication for all the children in the study. Two families used some American Sign Language (ASL) signs to support the spoken word. The researcher has intermediate knowledge of ASL and was able to understand the signs used by the children as well as to follow the parents' lead and use signs during play to elicit certain language skills.

Data Analysis

The focus groups were videotaped, audiotaped for back-up and transcribed by the researcher. The language interactions were also videotaped for later review. A research assistant was employed to assist with the recording equipment during the focus groups and language observations. The research assistant was a recent counseling graduate, was familiar with research procedures, and signed a confidentiality agreement. It was felt that the presence of the research assistant had minimal influence on the parents and children during the focus groups and assessments, as her primary role was to observe and manage the equipment. The families were not made aware of either the researcher or the research assistant's background in hopes that families would therefore not feel threatened or anxious in sharing their true feelings (Tattersall & Young, 2006). At the completion of each child language observation and focus group, the researcher would debrief and write memos reflecting back on the process (Miles & Huberman, 1984).

The data was analyzed with the purpose of answering the research questions and creating a phenomenological description of the experiences of the parents' grief experiences and perception of support. Wertz (2005) summarized Gorigi research outlining the steps involved in the analysis of phenomenological study. These steps include 1) listening and reading entire transcripts to grasp a sense of the whole narrative, 2) rereading transcripts and marking units of meaning which are of particular interesting to the phenomenon under study, 3) reflecting on each identified meaning unit to determine what insights it provides to the particular phenomenon, and finally 4) synthesizing the insights (Wertz, 2005).

In order to grasp a sense of the entire experience from the parents' perspective, the data was listened to several times (Hycner, 1989). First, the videorecordings were reviewed. Next audiotapes were transcribed. The video recording of individual focus groups were viewed a second time for the purpose of noting participants' own words to observe any non-verbal communication as they shared their experiences. The language observation and interactions were then also reviewed for the purpose of gaining a sense of the child's language skills. Based on the checklists of The Preschool Language Scale, each child's abilities was generally assessed as age appropriate or delayed.

The next step of data analysis involved the identification of "different core consistencies and meanings" (Patton, 2002, p.453). Each focus group was first analyzed individually. Notes of key words or phrases, patterns, interesting issues and common topics were underlined or bracketed in each transcript. A code or key word was assigned that captured the content of those sections. The code assigned to the text segments of interest was often a word pulled from the actual data. This process was done for each interview. After the individual case studies were analyzed, the next step involved a cross analysis of individual cases to collapse individual codes into themes (Creswell, 2005) This process occurred multiple times, providing multiple levels of coding. As the data analysis progressed, themes were collapsed into each other until no new themes emerged. The data analysis process was done manually because the researcher felt it important to be close to the data and have all the codes and themes visible at one time in order to appropriately sort the complex data (Creswell, 2005).

Credibility and trustworthiness

Credibility and trustworthiness are concepts in qualitative data that focus on the truthfulness of the description of the issue being studied, and clear descriptions of actions and decisions made by the researcher (Koch & Harrington, 1998). Credibility also refers to the extent to which data, and data analyses are believable (McMillan, 2008).

Qualitative data is assumed to be credible when it is detailed, consistent, meaningful and accurate.

One measure taken to ensure that the data collected was accurate and consistent was to provide parents with the opportunity to reflect on their focus group experience. This was done as a follow-up to the focus group sessions, whereby parents were asked to fill out a focus group survey to identify issues or items that they did not have an opportunity to discuss or were too uncomfortable to share. They were given the opportunity either to record in the open space provided or to contact the researcher directly for a private discussion. All parents completed the focus group survey. A sample is attached as Appendix E. All parents expressed appreciation for the opportunity to share their experiences and felt as though they were provided with enough opportunity to express their true feelings and experiences.

Accuracy of the data was also ensured through triangulation of the data. Triangulation occurred not so much through different sources of data, but rather through the collection of data at different times and in different places. The ability to connect with parents in different contexts; individually in their home environments and in a group setting with others who shared similar experiences provided the researcher the opportunity to ensure that the way and what parents presented was consistent.

Koch & Harrington (1998) propose that the researcher must keep the reader aware of their influences, or as they put it “what is going on” throughout the research process (p. 882). In doing so, readers will decide for themselves whether their interpretations are believable. The abundance of details provided in the verbatim parental quotes allowed the reader to judge the accuracy of the researchers interpretation. It is important for the researcher to demonstrate their engagement in the research process, an awareness of their own assumptions, their own familiarity with the issues, and how they accessed different views.

As the researcher had professional experience supporting parents upon learning of their child’s hearing loss, there was the possibility that this skewed the data collection or analysis. The researcher engaged in a continual process of self reflection regarding her own values and beliefs to be aware of how it might influence the data. The researcher approached this research, not with the expectation that families’ stories would fit into a particular grief theory or model of family centered service delivery, but rather with the understanding that individual meaning would be ascribed to their shared experience. These steps were taken to ensure that there was there was a match between the researchers interpretations and the true meaning ascribed to the experience by parents. The nature of the data collection, i.e. the focus group setting, helped parents to share honest feelings about their experiences. There was some initial reluctance to acknowledge grief, which was perhaps due the parents discomfort with the emotion but as focus group discussions progressed and one parent would acknowledge a certain feeling others became comfortable discussing it as well. This process was enabled by the researcher ability to remain open to design flexibility, and by allowing the data to unfold

as the research unfolded. Throughout data analysis, the researcher stayed in frequent contact with her supervisor who reviewed the data analysis and findings thus enhancing the credibility.

Chapter 4- Family Profile

The following is a brief description of each family with the names changed for confidentiality. This section provides a summary of the demographic data and presents parental views on language development as well as the researchers' observations, based on the normative guidelines of the Preschool Language Scales (PLS-4), of their child's language skills.

Claire and Eric

Claire and Eric were the mother and father of 16 month old Liam. He was their only child. They lived common law. Eric worked outside the home; Claire presently did not. Their son Liam was diagnosed with a bilateral profound hearing loss at 2 months. At 10 months he received bilateral cochlear implants. They described their son as being deaf and growing up with a hearing loss. For that reason they decided to pursue both spoken and signed language. Claire reported that her son is talking and has approximately 60 signs. . In observing Liam's communication skills, he demonstrated abilities that were similar to hearing peers in his age range as defined by the PLS-4. Claire explained her feelings about their language development decisions:

I wanted to do ASL because I know my child can see and if you tell me in a year that he is not a candidate for a CI because he has some weird malformed cochlea then I have gone a year without any language input to my son. One year olds have so much receptive language; they understand so much of what is going on around him them. I didn't want him to be one and not have a way to communicate, that's where all the frustrations come from, the meltdowns of a child not able to express themselves and that's all the time when their brain is developing. For me it was an emotional choice- to be able to communicate with my child using sign.

Eric also shared,

Everybody knows there is a fairly combative relationship between the methodologies, between AVT and ASL and so we were told if you decide to have

your child speak, than ASL would not be the best option for him but we just did listen and we didn't bother continuing a conversation with those people... That you sign with your child at home surely cannot be the thing that derails their acquisition of spoken language and it's the thing I posed to people along the way and I never received a satisfactory answer and that's why we ended up deciding we are going to pursue a bilingual approach for our child and I still believe that there isn't any evidence that suggests a visual language with that level of access to hearing [provided by the cochlear implant] will impede his acquisition of spoken language. I think it's a great decision that we made and I continue to believe signing has been the best decision for our child. It's been a great bridge to spoken language for him and he continues to progress at a very rapid acquisition of spoken language and signing.

Val and James

Val and James were the married mother and father of 2 years 6 months old Brody. He was their second born. Val was on an extended maternity leave from one position and James worked long hours outside the home. Their son Brody was diagnosed with a bilateral profound hearing loss at 3 months of age. At 10 months he received a bilateral cochlear implant. They both expressed initial language concerns because their son had not heard anything for the first 10 months while they waited for the implant. Val reported he recently started spelling, loves learning, language and sound and letters. . In observing Brody's communication skills, he demonstrated abilities that were similar to hearing peers in his age range as defined by the PLS4. Both parents felt that most people would not know that their son is deaf and they purposely grow his hair to cover the implants. The following statement reflected Val thoughts about language development.

We were told kids exposed to both languages never excel at either and at that point we completely shut down on sign language. I've been hard core about no sign language near my child. It's easier to sign than to speak so if he were exposed to sign he wouldn't bother, he's do what was easier instead of learning how to listen.

Zoe

Zoe was the mother of 18 month old Lucas. Her husband Tom agreed to participate but had a last minute emergency which kept him from the focus group discussions. Lucas was an only child. Zoe worked outside the home. Her son was diagnosed with a bilateral profound hearing loss at 2 months. At 9 months he received a bilateral cochlear implant. Zoe expressed her concern for the fact that her son is not yet talking and is displaying many signs of frustration. Lucas appeared to be delayed in his understanding of language and he did not utter any words or signs throughout the observation. His overall communication appeared to be delayed by approximately 6 months. Zoe shared her experience of being initially told that because they were considering a cochlear implant, Lucas should be kept away from signed language. What she shared about language development reflected some uncertainty in terms of her stance. She explained,

I understand why she [the therapist] thinks it's best for him [to avoid signing environments] I'm not totally blind but at the same time he is already having a hard enough time with learning how to talk. I don't want to mix him up, mess him up, send him off track. Our therapist feels like if he gets a grasp of sign he will favour using it because in a way it is easier, right. You just give your sign and that's it. My instinct as a mother is torn between her professional knowledge.

Rachael and Chris

Rachael and Chris were the married parents of 3 year 10 month old Levi. He was their only child but they were expecting a second. Both parents worked outside the home. Their son Levi was diagnosed with a bilateral moderate to severe hearing loss at 3 months of age. When he was 6 months, he received hearing aids and began attending Auditory Verbal therapy sessions. Rachael and Chris explained that Levi's speech is not

perfect but that he is a happy, affectionate child. In observing Levi's communication skills, he demonstrated abilities that were above hearing peers in his age range as defined by the PLS4. Rachael explained her feelings regarding her son's language issues.

In the beginning, people were saying, do you want your child to learn sign language or do you want him to learn how to speak even if he sounds like a dog and I felt like, the entire world speaks, I would rather that. Neither me or my husband know ASL so that would be like researching how to speak Japanese and raise our child to speak Japanese. It feels so artificial.

J.D. shared that "once Levi started talking it didn't seem worth it to pursue ASL".

Elizabeth and Rob

Elizabeth and Rob were the married parents of 28 month old Wyatt. He was their only child. Rob and Elizabeth both worked outside the home. Their son Wyatt was diagnosed with a sloping bilateral severe to profound hearing loss at 3 months of age and there was some concern that he hearing loss is progressive. Wyatt wears hearing aids and is developing both spoken and signed language. Rob explained that he and his wife felt that it was their son's right to "use ASL and also get cool hearing aids and go down both paths." Elizabeth explained, "For language development in general, I felt the earlier you introduce it the better it is learned and the less tantrums". In observing Wyatt's communication skills, he demonstrated abilities that were similar to hearing peers in his age range as defined by the PLS4. Elizabeth and Rob had a difficult journey in trying to get their son the services that were right for him. Elizabeth explained,

We were initially told your options roughly are, you can go oral or ASL or both the dual method. And we both thought well that's what we should do for a couple of reasons, well partially just because we are not good at making decisions and that's like not making a decision. And also it should be his choice, we are not going to say okay no hearing for you and later he'd be mad or we are not going to say okay no ASL for you and then later... It's like you decide when you are ready ... We started with AVT and when sign language came up our therapist seemed

sort of aghast and was like well don't you want him to learn to speak? And we were like well yeah- we want him to learn everything. And she was like if you are not concentrating on teaching him how to learn to speak he won't learn to speak. We explained how everything we've read says it's good to do both whether you are hearing or not hearing. The therapist made this nasty comment that we should just stick to the AVT and he'll learn to speak okay and that he won't have the deaf voice... and I just really got my back up and the more I thought about it afterwards the angrier I got. I felt like I hate IHP, I hate you all, you are so terrible and I'm so disappointed and angry. And this person is rude and biased and ruining my son's life and my life, I hate everything. ... You know I never thought about it but I just sort of wonder would we have fought for it if we weren't put in a position where we had to? If someone was supportive and not dismissive would we have just gone along? But I felt like, don't tell me I'm not going to do ASL, don't tell me I am some how preventing my child from speaking.

Hannah and Jason

Hannah and Jason were the married parents of 25 month old Ella. Ella was their second child. Both parents worked outside the home. She was diagnosed with a bilateral profound sensorineural hearing loss at 2 months and received a bilateral cochlear implant at 8 months. Hannah explained that Ella has had an easy time of it all, excelled more than expected and is graduating from her intervention services. Although Ella was very shy during the observations and interactions, she demonstrated receptive and expressive language skills that were similar to her hearing peers in her age range as specified by the PLS-4. Hannah explained that they see their daughter like “ she's deaf and she is always going to be deaf, I'm not taking her deafness away but I have given her a tool so she can communicate with whoever she wants. Hannah further stated,

We had to sign something saying we were not going to teach her sign language and that wasn't such a decision for me, not because I believe it because I know from learning that there is an advantage to learning lots of different languages at a time. But I don't know ASL and I also know that if you want to learn a language you can't do it once every five days, not one sign at a time, right. So how am I going to also learn ASL and do AVT. I am already trying to do so many hours of therapy a day and then add in ASL when I don't know it so I have to go out and learn it? So that wasn't such a decision for me.

Jason explained his view,

I feel confident about the decision that we made but I think part of participating in the CI study was to agree not to teach your kid ASL and with that maybe I felt an iota of pressure momentarily because I thought maybe I am cutting off an option that I know nothing about.

Julia and Adam

Julia and Adam were the married parents of 3 year, 9 month old Parker. He was their first born child. Both parents worked outside the home. Their son Parker was diagnosed with a bilateral profound sensorineural hearing loss between 2 and 3 months of age. At 12 months he received a bilateral cochlear implant. Adam explained, “it’s all too easy for us to forget on a day-to-day basis that our son is supposed to be deaf and in reality really is not”. They describe him as a happy boy that would not stop talking. Julia explained that they felt “forced to go in one direction, it was either cochlear implant’s or signing” because of the severity of Parker’s hearing loss. Adam explained an interaction where he felt professionals were trying to prepare them for “a different world, a world where the cochlear implant didn’t work...we didn’t want to get involved with that, that wasn’t where we were going.” He explained his expectation of his son’s language development with a cochlear implant,

By the time implanted children reach the age of three is when that many of them are even equal to the hearing patterns and language development patterns of their regular hearing peers. So that was our expectation level. That was great, three years. You know by the time Parker was 2 we certainly were thinking you seem to be pretty equal to if not talking more than cousin and friends and stuff like that so it, yeah, the expectation bar was set at such a reasonable level

Parker was a very verbal little boy uttering four to five word sentences. In observing his communication skills, he demonstrated abilities that exceeded those of his hearing peers in his age range as defined by the PLS4.

Christina and Derek

Christina and Derek were the married parents of 12 month old Noah. He was their only child. Christina was still on maternity leave but was getting ready to go back to work outside the home and Derek worked outside the home. Their son Noah was diagnosed with a bilateral moderate to severe sensorineural hearing loss at 4 months of age. He began wearing hearing aids at 6 months and began auditory verbal therapy. Christina explained that they felt AVT made sense and they never second guessed it, “we wanted him to speak, like if there was a really good chance we wanted him to be as normal as he could be”. Noah is making some sounds but both parents are worried because he is not talking yet. In observing his communication skills, Noah demonstrated language skills in his age category as defined by the PLS-4 Derek shared his feelings,

We still have a lot of questions unanswered just because he isn't talking yet and we are using that as a key, rightly or wrongly, we're waiting to see when he's going to start talking. You learn that speech can take longer to develop because of hearing loss so we still have a lot of questions, like is his speech going to develop properly? How long is it going to take?

Chapter 5 - Findings

The purpose of this study was to examine the emotional experiences of parents whose children had been diagnosed with a hearing loss through an EHDI program. It was expected that parents would share their feelings of grief in reaction to and in processing their child's hearing loss. The second purpose was to explore parent perception of professional support in relation to their grief processing, and decision-making. A third purpose was to gain an understanding about whether the support needs differed between husbands and wives. Three central themes emerged from data analysis and will be described in this chapter as well as subthemes for each category. The first theme refers to the feelings of grief that parents experienced centered on loss as part of their initial reaction to the diagnosis. Subthemes examined the loss parents experienced for what they had envisioned, the loss of the anticipated experience of motherhood and the different grief reactions of husbands and wives. The second theme refers to the paradox that parents experienced as they processed their grief, wherein they moved forward even as they stayed in place. Subthemes related the parents' experiences of moving forward emotionally with their experiences of embracing their child, gaining a sense of control, finding a new normal and developing an awareness of their child's skills and potential challenges. Subthemes related the parents' experiences of staying in place with their greater focus on child developmental outcomes, on social experiences that reflected feelings of isolation, and on moments in time when parents were brought back to their initial feelings of grief. The final theme addressed parents' experiences of being emotionally cared for. The subthemes in this category were the parents' perceptions of the initial support they received, the qualities they identified as important for a support

professionals, and experiences were parents accepted less than the high quality support they could identify. The final subtheme looked at the support needs of husband and wives.

Theme 1: Grief Related to Loss

Grief was a part of the experiences shared by all parents during the time of their child's diagnosis. These feelings, as parents described them, reflected the emotions identified in the disability related grief literature and included denial, disbelief, sadness and anger. All of the mothers and three of the fathers described physically breaking down in tears upon receiving the diagnosis. All parents shared their feelings of sadness and used words like "shocked", "overwhelmed", "hit with a concrete block" to describe their immediate reactions. Among the parents, a great deal of dissatisfaction surrounded the way the diagnosis was imparted. Feelings of dissatisfaction were also expressed about both the screening process and the diagnostic process. Parents' descriptions of these events were consistent with the literature that describes parents feeling that they received insufficient information from professionals and that they perceived professionals to be insensitive in the way the information conveyed.

When parents shared feelings, thoughts and experiences regarding their emotional journey a common theme emerged surrounding grief related to loss. These experiences can be further broken into the following subthemes: a) grief for the apparent loss of what they had envisioned, b) grief for the loss of the experience of motherhood, c) difference in the experience of grief between husband and wives

Grief for the apparent loss of what was envisioned.

The diagnosis of their child's hearing loss was unexpected by all of the parents. None of them had any experience or background with a congenital sensorineural hearing loss. Expectations about how parents would relate to their child and had been relating to their child while in the womb were grieved. Envisioned opportunities and activities for their child were grieved and the anticipated experience of motherhood was also grieved.

Parents shared their "profound reaction" and "devastation" that resulted from the loss of what they had expected. Eric described how music played a prominent role in how he envisioned relating to his child. He explained how he initially reacted to his child's diagnosis, admitting that at times he continued to have difficulty reconciling what he had envisioned for his child's musical experiences and what the reality of those experiences would be.

Eric: Honestly I was devastated I was completely wrecked by the diagnosis. You had expectations of what your life would be with your child and it's a great big slap in the face to say it's not going to that way it's going to be different relationship. I continue to struggle with some aspects of it even now.

Adam was overcome with emotion as he described his initial reaction to the loss of the visions he had for his child as he explored information that provided a glimpse into what his son's new reality might be.

Adam: I started looking at things on line and it wasn't three seconds until things come up like, "78% of Deaf people are underemployed.." and like... really a picture of dependence ... and it doesn't reconcile with the visions you have.

Like Adam, other parents shared sad feelings for their child and for themselves because of the perceived losses that a diagnosis of hearing loss indicated. Many parents described their first reaction: that their child's hearing loss meant they had to learn signed language. While parents described those feelings of sadness for themselves, like Hannah, they also shared how sad they felt for their child because many of the parents saw this diagnosis as something that would limit their child's opportunities.

Hannah: Initially I remember saying this is so sad for Ella, this is so sad for me, this is so sad for you... just a lot of feeling like this is so sad. Everything went through our minds like where is she going to go to school, my husband and I met at sleepover camp so we were like how is she going to go to sleepover camp.

Val: I was devastated. I thought immediately, oh my God he's not going to have the same opportunities as my daughter. People are going to think he is stupid – and I know deaf people aren't stupid but there is still this preconceived idea that if somebody sounds different they are not as bright as somebody else.

Christina also explained how she felt badly for her son because initially she intuited the ways her child's life experiences would be negatively impacted. She shared upon his initial diagnosis she was not aware that with hearing aids, he could learn to speak “normally.”

Christina: My emotions around that time were just feeling bad for Noah. You just don't ever want your kids to be sad or be teased and that's all we could think of. The playground, not hearing something and having to ask five times or speaking differently, just struggling at all.

Claire describes her feeling of sadness for her child as a result of her perception that his hearing loss had lessened the bond she felt she had been establishing by talking and reading to her son while in utero.

Claire: The most upsetting thing for me was that... see you talk to your baby when he's in your womb... and that was the worse part, when I realized he hasn't heard a thing...he hasn't heard when I read to him. He isn't born knowing my

voice, its all that stuff. It's that when your baby is in the womb, hearing is the only sense they really have. So to feel like my child was alone, I felt sad for him that he was alone.

Grief for the loss of the anticipated experience of motherhood.

Each mother shared feelings about grief and loss not just for what they had envisioned for their child but also for how they envisioned the experience of motherhood. Some mothers talked about how their grief was related to the loss of opportunity to bond with just their child, before facing the complicated emotions and decisions surrounding their child's hearing loss. Some mothers also shared how processing the diagnosis was complicated by the basic fact of being a parent to a newborn. Hannah explained her grief about losing the simple opportunity to enjoy her child during their first few months together since their lives were complicated by diagnostic procedures even after they received the confirmed diagnosis of hearing loss.

Many parents shared their stories about being in denial after the first few initial screenings. Many went home and did the testing themselves, banging pots and pans, carefully watching for reactions to loud noises and finding moments when they were sure their child responded. Despite her denial, Hannah expressed her suspicion that her child might have a hearing loss, and preoccupation eroded her sense of newborn elation.

Hannah: Fear was planted in my head [after the screening]. I cried many times those first 8 weeks so I do totally feel like those first 8 weeks were taken from me. I never really got that... you know you are so tired... I never got that elated here's my perfect baby- it's taken away very quickly. I really tried once we knew for sure, I really tried to enjoy it. Because I was like, okay this is it, you are not going to be breastfeeding again you're not going to have this yummy baby again. But of course it was taken away.

Similarly Val shared her feelings about the loss of her anticipated experiences of motherhood, recalling in her son's first year how many of her son's first milestones were marked by difficult emotions or experiences.

Val: I feel sad again when I go back and replay things, your child's first steps, the first time your child speaks. And you do go through that with a normal child as well but with Brody it was just such a stressful and sad emotional roller coaster for that first year.

Rachael's comments indicated instead how difficult the newborn method of discovery of hearing loss could be. She explained feeling as if an unexpected label had been put on her child definitely and suddenly. For Rachael that process was more jarring than the gradual learning about the ways in which her child might be different.

Rachael: I was basically devastated, I wept and wept for weeks. No child is perfect but somehow you would rather learn that when they crash the family car. Yeah you just have this definitive, your child is flawed, and here is their specific flaw, so just deal with it. That's just a different process than slowly learning how each human is different and this is how your particular human is different from other humans. This is just sort of a like here's a label, here's a badge, here's likely prognosis and it's just kind of a slap in the face. I don't know it's like being shocked very suddenly.

Two fathers—Derek and Adam—commented that it was their role as a new parent that they found difficult, as opposed to experiencing the difficulties of being the new parent of a child with a hearing loss. This contrasted with the mothers' shared feelings. Coupled with their feelings of new motherhood were the unexpected challenges of mothering a child with a hearing loss. Four mothers commented about the fact that their newborns did not sleep through the night and in one case continued not to sleep through the night, which compounded their grief and taxed their coping skills. Elizabeth shared

her difficulties in attempting to process the information about her son's hearing loss. It took her 9 months before she felt prepared to advocate for her son.

Elizabeth: I just found it all so overwhelming, that whole new parents anxiety. Partially just because nobody was sleeping through the night so we were all just sort of walking around in a haze. I remember researching on the internet in the middle of the night while breastfeeding and I have pages and pages of links that I don't even remember what they are anymore. I think that some people forget that you are going through that part as well. I am just sort of trying to deal with having a little tiny baby and then it's like trying to raise this little baby that has extra stuff to deal with.

Elizabeth's husband Rob, shared how he "never thought far ahead" in terms of his expectations of parenthood, his relationship with his son or expectations for his child's life though he did share an experience that perhaps reflects some difficulty in reconciling his perceptions of parenthood when he described feeling "weird" about techniques that his wife used to soothe their child. While he recognized that some typical parenting behaviours did not fit, he experienced some uncertainty about what he could replace them with.

Rob: When Wyatt would cry before we knew fully that he was hard of hearing, [my wife] she would shush him to sleep. And I thought well, yeah, we did know that he was hard of hearing so I would feel kind of weird that she'd be shushing him and he wouldn't be able to hear.

Claire explained how the added demands of appointments, "one out of every 5 days", to be coordinated around sleeping, feeding, and changing was stressful and made her feel like she missed out on some of the early experiences of motherhood, like coming to know her local mom community.

Claire: It was really crazy ... I think I missed out on my local mom community because after the diagnosis we were just gone. We were at appointments or I don't know we spent the time researching deafness.

Julia shared how she felt awful when she would take her son to mom and me groups and the hearing aids would squeal and garner everyone's attention.

Julia: We'd go to moms and me groups and your kid would turn their head and the hearing aid would squeal and it was like, "what's going on over there". It was awful.

Different grief reactions in husbands and wives.

Part of the reason for separate mothers' and fathers' focus groups was to determine whether their needs for support were different from each other. Even before examining their support needs, it was important to attempt to understand whether there were any observable differences in their grief reactions. Whereas between both mothers and fathers a reluctance to talk about grief was obvious, this was more overwhelmingly the case for the groups of fathers. Most of them identified their way of grieving as an extension of their extant personalities before their children were born. James, Chris, and Rob explained how they saw themselves as "calm" and "sensible" individuals; therefore they reacted that way in response to their child's diagnosis. Zoe—whose husband was unable to participate at the last moment—had an opposing experience, explaining she and her husband experienced a role reversal when her son was diagnosed with his hearing loss. Her husband grieved in a different way than he had to previous life events. The role reversal was unexpected.

Zoe: Usually my husband is more of the backbone and oh okay let's pick ourselves up and dust ourselves off. But we had a role reversal- he was the one weeping and I was the one like, okay snap out of it. I kind of almost found that shocking- I was like wait a minute, so I think it brought out different sides.

It took longer to reach the point where some fathers felt comfortable in discussing or acknowledging emotional reactions. Fathers' tended to discuss how rather than

grieving themselves, they helped their wives to cope with their grief. Chris' comment reflected both sentiments. He initially shared how he was not upset by his son's diagnosis and saw his role being to help his wife grieve. Later in the discussion he shared that his being upset was what helped to comfort his wife.

Chris: When the initial information came through I did more comforting of my wife than she did of me. I was upset but I think that was actually part of what was comforting to her... As she would talk about it, I would talk about it.

Rob also explained how because he was not that upset by his son's diagnosis he was able to focus on being there for his wife.

Rob: I think that me focusing on Elizabeth helped. Me being mission orientated and being a man rather than working with the intangible. It was very helpful for me to think that way.

Another commonality amongst the parents was an acknowledgement that some husbands and wives did not really talk together about feelings of grief. Like Rob, Adam and Derek shared their belief that discussing emotions was not part of what husbands and wives did together. Their comments supported the stereotype that men do not talk about their feelings. Val also explained that her husband did not like to spend time talking about sad things.

Val: [My husband] he's a very quiet, reserved, private person – he works really hard and comes home to his family. He doesn't necessarily hang out with a lot of people talking about disabilities. He wants to talk about what's going on in peoples' lives and the positive parts of it, not what is pulling them down and that's just the way he is.

All but one of the mothers described their initial means of grieving an intense and sad reaction. Some mothers, like Val and Rachael, even shared that they did not feel strong enough to deal with the diagnosis of a disability.

Rachael: I'm not the movie of the week mother that would be able to surmount all odds.

Val: I am not God, I am not the person to be having a child with a disability- there are stronger more connected people out there than I am who will take this on and love any step of this journey more than me.

For the most part, mothers and fathers were very aware of how their partner grieved. Only in a few instances were there differences in how one partner described the other's grief reaction. Rachael described how she perceived her husband, Chris, to have grieved for the loss of how he envisioned relating to his child through music. But her perception of how her husband felt was different from how he explained his feelings. As previously indicated, he "wasn't upset at all". Chris explained this was because of his involvement in the world of music, "it's not an usual thing in my world and I wasn't terribly upset at all."

Rachael: He was very upset because music was tremendously important to him. Before Levi was diagnosed he had already determined when Levi would be introduced to his first musical instrument and what teaching methodology would be used and so to suddenly be told that your son would not be able to appreciate one of your biggest passions was hugely upsetting to him. We mourned different things.

In another case, Elizabeth described her husband as an "emotional person" who was, of course, worried about his child and in need of some support. Where Elizabeth mocked the stereotypical notion of "man", Rob used the term to genuinely describe how that behaviour supported his wife. She acknowledged that he may say differently and he did.

Elizabeth: I felt like people were offering me support and not him as much because you know—he is man —hits bear with stick or something. Like he's not

worried about the baby or something but he is a very emotional person as well. Maybe he will say differently but I feel like I got a lot more support than he did.

Summary.

Four of the fathers and only one of the mothers were reluctant to talk about grief or did not feel that grief was a part of their initial experiences. Often when those fathers were asked to speak directly about their emotions surrounding the initial diagnosis, the conversation turned to their experiences of moving forward. This difference in how fathers and mothers talked about emotions will be explored further in later sections. Chris, Rob and Julia all indicated that it was just a matter of acceptance: they accepted their child's diagnosis for what it was and moved on. This theme, too, will be further explored in the following section. For the other three fathers and seven mothers there appeared to be a significant amount of grief early on in the process of diagnosis related to their perception of a variety of perceived losses. Parents needed to clarify that much of this grief was short lived and, only experienced for a "few days" or for "the first few weeks" following the diagnosis. Adam explained that because of his son's language outcomes, he did not feel "justified" in having the difficulty he had recounting his earlier experience. Derek's explanation demonstrated an attempt to minimize his perceived grief.

Derek: When Christina came home with Noah she was in tears and it was just like, you know I can't believe our baby's not hearing. He's not going to be able to hear and all that stuff. That was a rough day. I think we're pretty level headed people, not highly emotional ... I mean we take most things in stride and we kind of did with that, like we'll get through it, it's not the end of the world but it's right up there.

The next theme focused on how families processed their grief. Here the concept of paradox will be introduced to describe how parents discussed how they emotionally

moved forward from grief and sadness yet continued to realize some of those experiences.

Theme 2: Paradoxes in Processing Grief - Moving forward and Staying in Place

While parents described themselves as moving forward and leaving behind their initial grief experiences, their narratives demonstrated that they lived with paradoxes. Merriam-Webster online dictionary offers as one definition of paradox “one (as a person, situation, or action) having seemingly contradictory qualities or phases”. Parents’ experiences reflected two concurrent, yet oppositional, thoughts about how they processed their child’s diagnosis. They expressed both concurrent and contradictory thoughts about emotionally moving forward, even as they continued to grieve. Without being provided any direction about or in regards to a proposed grief theory within which to frame their experiences, the following quotes reflected how parents processed their grief, experiencing both joy and sadness.

Emotionally moving forward.

Many parents shared experiences related to positive changes in their feelings over time from the initial grief experience. Moving forward was exemplified as they shared experiences in 1) embracing their child, 2) gaining a sense of control over the situation, 3) adjusting their perspective and seeing their child’s hearing loss as the new normal and 4) developing an awareness of potential issues and strengths.

Embracing their child.

Four fathers commented on how the experiences of loving and celebrating their child lessened or took the focus away from grieving. Eric explained that his love for his son surpassed his grief, “we love him so much that we don’t care anymore”. Rob, Chris

and Jason explained how they looked to their child to gauge how impacted they should allow themselves to feel by the hearing loss. Rob did not perceive his child to be negatively impacted by his hearing loss therefore saw no reason to perceive the situation negatively.

Rob: The greatest teacher here is Wyatt himself –he doesn't feel impeded so if Wyatt doesn't know any different and I don't know any different.

Chris described that the love he felt toward his son helped him to process his grief. Similar to Rob, when Chris looked at his son he was reminded that his son was not “suffering or deformed” but rather was happy, loveable, and affectionate.

Chris: I think the key factor was our affection for Levi- the fact is that no matter what you could possibly imagine as the horrible aspect of his diagnosis, looking at him made that go away.

Val, Christina and Julia also shared their feelings about the joy they experienced noticing and celebrating their children's growth, successes and accomplishments. Val shared how much more meaningful her child's successes were because of the challenges he has faced and the obstacles he has overcome.

Val: I really feel blessed to have had this opportunity with my son. It's wonderful when a kid with issues and stumbling blocks, oh my God is it ever an incredible feeling, when they accomplish something. It is 10 times the rewards you get than with a normal child with no issues. I really feel blessed to have had the opportunity to have had the implants.

Julia and Christina also shared how much more joyous celebrations were when their child's achievements were so much greater than what was initially anticipated. Another commonality was the perception of gratitude. Val's feeling of gratefulness tended towards the technology that she was able to procure for her son. Other mothers expressed gratefulness for their child's achievements. The following statements reflected

their shift in expectations from how they felt at the time of the initial diagnosis to the present time.

Julia: From one day thinking that our lives were ruined, your child will never learn to speak and will go to separate school from everyone else, to watching this marvelous amazing miracle happen. It has made my kid a smarty pants going to those AVT sessions. It made us very grateful.

Christina: Having a child with a special need in this case a hearing loss, it just makes you more grateful and it puts things into perspective. And you are just so excited and so proud of whatever they do and it just makes it even more special.

Zoe's son was not making the same language gains as the other children in this study; some of her statements reflected her inner struggle to reconcile her expectations for her son's language development with cochlear implants to the reality of what he has actually been capable of communicating. Zoe explained that to help herself process her grief she began to focus on the positive outcomes. If perhaps his speech was not developing, he was at least provided with access to sound.

Zoe: If you go "errrr", he can go "errrr" so I know he is hearing. So that to me that's worth it because I know he's hearing and he was never able to hear I love you or anything like that and now he can. Yes he had a rough road afterwards but I think it was worth it for that amount of time to give him that gift of hearing as many CI parents say, it's that gift of hearing.

Three of the four fathers, who shared anecdotes about embracing their child as they are, also shared how their child's diagnosis of hearing loss enabled them to really focus on how they connected and related to their child. For Rob that meant making a point of spending quiet time together, outside the focus on talking and signing. Chris described how "the positive thing is when he doesn't have his hearing aids or as we call it his 'ears' in, we've gotten to cuddling while we talk". Eric joyously shared how he came to realize after his initial explorations into Deaf Culture and signed language, his son's

hearing loss provided him with a whole new way of relating to his child that involved participation in a new culture.

Eric: I saw this as an amazing new world that we were invited into. The reality is we are connected to another group of people who share the commonality of having a child with a hearing loss. We are part of Deaf culture, we go to Deaf culture events, we are part of the world of ASL because we do sign with our child and we do AVT.

Many of the parents in this study used the term acceptance in that they talked about having just accepted their child's hearing loss and moved on.

Chris: For me it was more accepting. You know it was more I accept the situation that's there.

Rob: With me I think I just carried on. It was just how things are and this is how things happen.

Julia: I guess my style is, it just is what it is and just deal with it. That sounds a little harsh but that's truthfully how I just accept things the way things happen, truthfully.

What the term "acceptance" meant to the parents who used it did not seem exactly clear since these same parents later inadvertently used words and shared experiences contrary to the term. As compared to other parents, Zoe outright articulated her struggle with the acceptance. In the following quote she acknowledges how she knows that she should accept her son as he is yet identified her ability to do so.

Zoe: This natural progression that is suppose to happen even when they have implants is not taking place for my son. But I have to try to step myself away from the picture and say whatever Lucas will do is what Lucas will do and that is the end of the story. Because otherwise I will drive myself nuts and then it doesn't help Lucas, right? Like thinking that he is always different.

Gaining a sense of control.

In sharing how the parents emotionally moved forward, many described gaining a sense of control or purpose over this situation in which they initially felt none. Parents

described rapidly acquiring the knowledge that they needed in order to move forward. This means of processing grief was applied equally by both mothers and fathers in this study. Taking action for all the parents meant connecting to intervention programs. Taking action also took on other forms for some of the fathers, who expressly carved out actions that they took responsibility for in their partnerships. For Derek that meant being the one to research the medical literature, and for others, like James, it meant to financially provide so his wife could stay home. Both fathers and mothers initiated information gathering but for the majority of them taking action was tied to intervention. There was an expressed sense of relief from many of the parents whose children received cochlear implants when they were connected with the cochlear implant stream.

These quotes from Rachael, Hannah and Christina exemplified their decisions to focus on “the next steps” which helped them to move forward and away from their grief. Many parents shared positive feelings in finding a system in place in which they simply followed the identified steps. Rachael’s quote indicated how she busied herself setting up appointments and making phone calls. Following steps provided her with a sense of purpose and direction.

Rachael: While the first period immediately after the diagnosis was very upsetting, you then get into this, I will make these phone calls, I will make these appointments, I will be there on time, I will do this and this. This set procedure and you can sort of hold on to the rungs of that ladder as opposed to feeling completely lost.

Hannah also shared how the therapy gave her a focus, an outlet to devote her energy as they waited to learn whether her daughter would be an implant candidate.

Hannah: I just went, okay now what is the next step. I was already focusing on doing therapy with her and seeing that she could get the most out of her hearing aids at least and keep that nerve alive. The doing was a coping mechanism.

Hannah further explained how the news that her daughter was an implant candidate came earlier than she had expected, even before she was ready to move forward with that decision.

Hannah: The doctor told me , “I’m ready, let’s go.” I’m like, what do you mean you’re ready? I’m not ready. I haven’t done any research because I didn’t want to do any unless I knew it was an option. And I’m like okay just give me a month, I’ll come back in a month.

While moving forward was positive for many parents, like Hannah, those mothers whose children received cochlear implants commented that the time period, between waiting to learn if their child would be an implant candidate or not was a very emotionally difficult time.

Christina acknowledged her desired not to “dwell” but rather move forward with “what we have to do”. She explained how focusing on the next steps allowed her not to remain in such a heightened emotional state. For her, “the more I think about things, the more I can come up with all the bad scenarios.”

Husband and wife, Adam and Julia expressed appreciation for the support from professions who informed them about the next steps. Adam recounted how he spent little time being emotional but rather appreciated being directed into action.

Adam: We went from the devastations quickly into action. We got over the emotional day and into the very quick, like we had solutions proposed to us at the same time as the diagnosis which was really good. We were boom, boom, boom, boom, right into sort of the cochlear implant stream so we were very quickly thrown into, “what are we going to do about it.”

Husband and wife, Eric and Claire, described gaining a sense of control in the collection of information about all of the options. Eric defined the process as intellectual when he explained his open-mindedness in seeking to understand all the information and options presented. Claire also wanted to know about all her options but explained, despite some professional reassurances, she did not want to count on only one type of intervention to ensure her son's access to language.

Claire: I am proactive and I also wanted to know what all my options were. We have looked at different school settings and we brought our 10 month old child to a sign support class but as we got closer to the date and all the doctors were like your child is going to be mainstreamed like we really didn't know and I am not one to take things for granted or to just put all my eggs in one basket.

Husband and wife, James and Val looked forward to what their options were once they found out about their son's hearing loss. James explained that they were given options but he felt "it was clear where they were coming from and what their recommendations and preferences were. But we came to the same conclusions." Val described her relief upon hearing that due to her son's hearing loss being genetic he would be an "excellent candidate for a cochlear implant."

Val: I just went, phew, okay we have a lot of work ahead of us perhaps but that's fine. I can take this all on as long as I know we have a good shot of having a child who can assimilate quite well into society, then it'll be fine.

The new normal.

A common thread among the parents' experiences evolved as time elapsed and their child developed, particularly in terms of speech; their child with hearing loss became their new normal. Even though it was the new normal that parents discussed, for most parents it meant that their child began meeting the same milestones of hearing children. As parents gained familiarity with hearing loss and established regularity in

their routine, their child's diagnosis normalized. The majority of mothers—Christina, Claire, Julia, Elizabeth, Hannah, Rachael, and Val—made statements indicating that their child's hearing loss had become normal. Jason's statement reflected the sentiment of changed feelings over time, from feelings of loss to feelings that his child was the same as other hearing children.

Jason: I had the greatest sense of loss at the beginning... I say at the beginning because when I see her now ... for all intents and purposed she is normal. And I don't like to use the words normal and not normal but she behaves and responds like a hearing child. But my experience especially at the beginning was very much one of sadness and loss and was very difficult. But seeing her now, how she is has completely turned that sadness around.

Adam and Val both shared how their child's hearing loss has become such a normal part of life that they often forgot that their child was deaf. Adam shared his transformation.

Adam: It is all too easy for us to forget on a day-to-day basis that he is supposed to be deaf. And in reality, is not, other than dealing with some wires and batteries and stuff like that, it's hard to put a hat on, but this kid is rocking and rolling and talking. You just learn so much more and you experience for yourself how life is like and it's just normal now. This is, that's Parker, it's really fantastic.

Awareness of child's skills and potential challenges.

The ability to acknowledge a child's strengths and possible weaknesses is a positive step in processing grief because it is indicative of an awareness of their child's reality . For the parents in this study, an overwhelming awareness of their child's language development skills and some acknowledgement of the potential challenges that their children might face emerged. The challenges briefly shared centered on the social and emotional impact of hearing loss on their child's later years. Claire explained how she looked ahead at the next challenge, struggles with her son's social development. Eric also shared how he wanted to understand what challenges his son would face socially and

emotionally, “looking 20 years down the road”. Jason acknowledged that while he viewed his daughter as “normal” now things might change for her when she started to question why she was different from other kids. Hannah also shared similar views about the change in her feelings over time, while acknowledging that difficulties loomed.

Hannah: A lot of that despair and sadness of what’s going to be is gone. I don’t have any concerns about how she is going to speak, how she is going to hear, how she’s going to do in school. I mean I still obviously have my social concerns because she is going to be different and that is going to be a challenge but I worry about that with my older daughter...

Rachael’s comment reflected a similar change in her feelings over time. After finding out she was pregnant with a second child and being asked if she would want to know if this baby was deaf, she explained how her experience with her son had shown her that there was potential, despite hearing loss. Nonetheless, Rachael admitted to having some worries about the challenges her son might face. Though in both the previous and the following quotes, these mothers quickly acknowledged that these challenges did not relate solely to their child’s hearing loss.

Rachael: It doesn’t matter if I am carrying a deaf child because once you are in the system and you’ve seen how the kids are perfectly viable - I mean he’ll probably have a problem getting a date when he’s older but people have problems getting dates everywhere.

Summary.

All of the parents interviewed in the study shared ways in which they positively processed their initial grief after receiving their child’s diagnosis. Many of the fathers talked specifically about finding joy in their child and many of the mothers shared how their joy was related to their child’s successes. Parents also highlighted that moving forward with intervention services helped process their feelings of grief. It was common

amongst the parents to describe that this strategy was their preference over other emotion focused processing strategies. Parents also shared how they had come to accept their child's hearing loss in their descriptions of the "new normal" or despite their awareness of future challenges. While parents described each of these elements as positive adjustment to their child's hearing loss, inherent in some of their narratives and even in statements were paradoxes in their perceptions and feelings.

Does moving forward quickly allow individuals the opportunity to process emotion properly or does it enable emotional suppression? Is acknowledging a sense of normal, but only in terms of a normally hearing child, really indicative of acceptance? Do parents demonstrate an awareness of their children's future challenges when they only acknowledge those challenges that are not unique to disability? These questions lead to the following subthemes that present expressions in opposition to the above shared categories.

Staying in place - continued grieving.

Paradoxes also became more evident as parents shared their experiences and feelings in contrast to the messages of joy and positivity. Parents admitted some experiences indicative of continued grieving, time in which they felt similar to the way they felt when they initially received their child's diagnosis. This suggested the ways in which they were staying in place as opposed to the above-described experiences of moving forward away from grief. In paradox, parents held these two oppositional thoughts at once. It is important to note that these following sections are not intended to negate the positive ways families felt they were processing their grief, but rather to exemplify how these two processes existed simultaneously. The subthemes in this

category that reflect parents' experiences of staying in place are: 1) the greater focus of each parent on developmental outcomes, 2) the social experiences that reflected feelings of isolation, 3) the moments when parents were returned to their initial feelings of grief.

Outcome focused.

As previously mentioned, the experiences shared by the parents interviewed reflected a great deal of focus on their children's developmental outcomes. For some parents, the concern focused on the yet-to-be-attained language milestones; other families expressed earlier fears at the possibility that their child may have challenges in addition to their hearing loss. Mothers shared the burden of responsibility and pressure they felt for ensuring that their child obtained optimal spoken language outcomes.

Only three children were observed with language skills that did not surpass their age category based on interactions derived from the PLS-4. . The parents of these three children shared feelings of concern and anxiety about their children's language development. Elizabeth shared her struggle with the fact that despite her love for her son she still experienced concerns that the quality of his speech might always be impacted.

Elizabeth: I start to worry like what if he doesn't learn to talk, what if his voice, what if his speaking level... this is it. And for the rest of his life he is going to be saying gord and guy for four and five. What if he is peaking you know and I do still worry. And I mean I love him to death, I love him to death but I worry about him and it breaks my heart, it breaks my heart.

Although husband and wife, Derek and Christina's son was only one, they expressed concern that he was not yet talking. Their description about the way they felt suggested that they were emotionally on hold, not yet able to process feelings about their child's hearing loss until they knew more about his language development.

Christina: How he's doing is kind of unknown right now. I mean he's making sounds and kind of moving along, I think as he should be. Everyone seems to say so but yeah until you hear a word you wait to see if the hearing aids are working.

Derek: So that period of time from finding out until now I think we still have some ups and downs in terms of you know how are things going to turn out for us... and I think we are relying on him developing speech as the first big thing and that hasn't happened yet so we are early stages.

A number of parents expressed fear regarding the possibility that their child may have other developmental issues. Rob and Val shared how these were their initial feelings but Derek admitted that it was something with which he continued to struggle.

Derek: You read a lot about children that the hearing deteriorates and that could happen with Noah and is that happening now. Is he in six months going to be a candidate for a cochlear implant and should we be going that route? I guess there's just uncertainty right...is he going to have other issues, you read about children with hearing disabilities sometimes they have other disabilities. So there are a lot of things out there that we still wonder and it keeps us up at night.

Zoe also indicated that she feared her son might have delays in addition to his hearing loss. Her fears were founded on the basis that he had not made the "natural progressions" that other children with cochlear implants had made. He also appeared to develop later in other areas. She hoped that her son's life would not be any further complicated than it already appeared to be.

Zoe: I think my concern is that he is already deaf. I don't want him to be delayed in everything else. He didn't roll over until literally 9 months, he didn't eat solids until a little while ago. Like everything was just so slow for him. He's already deaf. I just don't want him to have any other battles.

Some of the parents' shared experiences reflected a focus on the attainment of other developmental milestones. Claire visited her doctor because her child still was not sitting unsupported. Val described her anxiety when her son was not early in reaching crawling milestones. She worried that he may have issues in addition to his hearing loss.

Val: We were just overly cautious about what sort of issues are out there associated with deafness. And as a mother whose still antsy about the whole thing I didn't want to hear the term syndrome. And Brody was late to turn over and start crawling and I was anxious that there was something wrong with him.

As a result of the parents' heightened focus on their children's developmental outcomes, many of them felt a great deal of pressure about working on therapy and modeling language skills for their child. The mothers in all families attended most of the therapy appointments with their children. Three mothers—Claire, Val and Zoe—described the heavy weight of responsibility that they felt for their child's language development success. All stated that they would be to blame for not working hard enough, if their children failed to make the appropriate gains. Zoe struggled with this perceived pressure.

Zoe: I feel like there is this huge responsibility on my husband and I to perform at some peak level so he gets optimal development. And it's like this weight on my shoulders that if I don't do something properly his speech is going to be nil. It's really upsetting to me if I do the wrong move it'll be the life and death of his speech. That's really upsetting to me because the reason I got cochlear implants is so he has that ability.

Val also shared the weight of responsibility she felt working towards therapy goals, indicating that she had extended her maternity leave to avoid leaving the responsibility "in the hands of a nanny". Her quote may have reflected some unacknowledged strain on her marriage as she and her husband viewed the importance of therapy follow-through differently.

Val: I think the difficult thing was when we started therapy, my husband never goes to AVT I was like no we have to talk to him like this, "upupup" and "ah ah ah aahh". He would read to him and I would be like James you have to fluctuate your voice make it more interesting, come on. So I was like cracking the whip at him saying my son won't make it if he doesn't alter his voice – but my husband just did the same and Brody is fine so obviously it didn't make that much of a difference... I just feel like if this child doesn't do well it is all my fault.

Christina shared her feelings of guilt for perhaps not doing enough every day to further her son's language development. Christina questioned whether she should be returning to work because her son would be in daycare which she described as a less optimal auditory environment. Both Val and Christina's comments reflected how these mothers felt some limitations and struggled with the difficult decision of going back to work because it involved entrusting "therapy" to others.

Christina: I feel a little more guilt like oh I should have talked to you more today. I should be talking to you all day, talking about opening the door, changing your diaper and this and I just don't think I would have felt the same way if my child didn't have a hearing loss. I am going back to work in September and you wonder will he doing better if I stay home?

Elizabeth, Eric and Rob shared how they also struggled to find a balance between working on their therapy goals and just being with their child. Elizabeth's sentiments reflected her frustrations with finding that balance.

Elizabeth: It's like let's talk about the letter "s" all day long, look a snake sssssssss. It's really hard to just sort of relax and be a normal person without. you know, like ah here's a chance to sneak the letter "s" into conversation and see how he reacts. Yeah it just drives me crazy that we have to think that way. I just want to hang out with my baby and not have to think about that, you know focus on his enunciation of certain consonants and stuff it's just frustrating- I'm not that interested in snakes...

Eric also shared an awareness of his struggle to achieve some balance in terms of working on language goals and relating to his son in other ways. He eloquently articulated how he did not want to define his son only in terms of speech and hearing but still wanted to acknowledge that his hearing loss is a part of who his child is.

Eric: I think one thing that I am cognizant of is like you have to incorporate AVT into your daily routine and so we are always doing the, “can you hear that, what about the car, it makes this sound and that was this” and after a while I start to think oh man, I don’t want to relate to my child always through the prism of AVT techniques. I worry sometimes that we are defining him too much by his hearing loss and sometimes I have to stop myself and say, would I be doing this if he were a hearing child?

Following what Eric shared during the focus group, Rob had a revelation about how “on” he actually was throughout the entire day with his son. This revelation revealed some contradictions with his previously shared experiences where he explained consciously making the effort to relate to his son in non speech and language terms.

Rob: I feel sometimes like we are doing a lot of techniques and a lot of you know I want to make sure that the listening environment is really good for him. There’s always something every second of the day. I’m really on all the time, all the way up to bedtime reading him a story, wow I didn’t realize how on I am all the time.

Chris, Jason and Adam shared their somewhat opposite feelings about therapy as compared to the other fathers. In listening to others discuss their focus on therapy, two fathers joked about how they now felt guilty about the lack of focus that they personally placed on therapy. Chris explained that he felt the responsibilities related to therapy were no different than what he would do normally with any child, for example reading stories, or pointing out fire trucks. Sometimes they get to those tasks and sometimes they do not.

Chris: We take him to the classes and so forth and we’ll do the exercises that they want and some weeks we don’t do the exercises at all because they get left in the bag. I don’t know that we are doing anything that we wouldn’t do if his ears were fine.

Jason explained that he did not understand the therapy or see it as present in their day-to-day life. Instead he relied on his wife to incorporate the therapy.

Jason: I’ve been to therapy, I sort of see what goes on I don’t really get it but I sort of rely on my wife thinking that because she is in the medical field that maybe she’s doing something but I don’t see it in our daily routine.

Isolation.

Parents in this study struggled and in some cases were hesitant to identify their children as having a hearing loss. This struggle reflected in comments where parents used descriptions like “deaf and yet not deaf”, to describe their child. Some of that struggle resulted in parents being very uncomfortable with signed language and Deaf culture, in part because they did not see their children having a place in Deaf Culture. For many of the parents in the study, it was not important to connect their child to other children with hearing loss. Some parents purposefully chose this in order to limit exposure to signed language feeling that it would impact successful spoken language outcomes. Other parents suggested that the difficulty in establishing those connections was not worth the trouble that would be encountered accessing the services. For example, Rachael shared the difficulty encountered in having to travel great distances to access that type of programming.

A discussion among the parents explored their feelings connecting with other parents who were in similar situations. The common reason for wanting to avoid those situations was to avoid the pain that they might feel in being exposed to encounters that did not resonate with their own expectations and hopes for their child. Many parents did not initially want to be connected with other children and parents. Hannah did not want to connect with other families of children who had cochlear implants until she knew that her child would be a candidate. Rachael described a perceived negative encounter with another mother whose child had a hearing loss. This encounter led her to believe that support services were not helpful to her processing of grief since another child’s reality

might not be her son's reality. Even if it were, she indicated that she would rather discover that reality naturally as opposed to having to ruminate about what was to come.

Rachael: The one time we went to [a specific intervention centre] Levi was a happy one year old bouncing around and there was a very unhappy three year old there. And I looked at this child and thought, oh my God this is a very unhappy child and I can see she is unhappy, its mother can see that its unhappy and is this the future? And if it is the future I don't want to think about it right now I'd rather just have that future come to me. So to some degree going out into the community to find support services I knew would give me information to sadden me and ultimately not be relevant, at some point I would rather be in the now.

Parents shared wounding encounters with other parents of children with hearing loss and even strangers. Some parents explained their withdrawal from other parents and children who signed, or identified themselves with Deaf culture, because of the sadness it made them feel. Because of Zoe's son cochlear implants, which she perceived was viewed negatively by the Deaf community, she remained apart from Deaf culture.

Hannah described a saddening social experience in a signing environment. She was struck by the realization that while she could not communicate with this group of people, this group of people was similar to her daughter. Nonetheless, her daughter could not communicate with anyone. This was a painful realization for Hannah, highlighting her daughter's different-ness and what Hannah perceived as her limitations. This realization reinforced her decision to provide their child with a cochlear implant.

Hannah: So we went to this fun day at [the intervention centre] and everyone was ASL. My husband and I were in tears. We were like we cannot communicate with these people and these people are exactly like our daughter. Like this is...she is them, we, this is us. And like we cannot communicate with, like my daughter cannot communicate with anybody. And then and I was like I couldn't imagine putting Ella in a situation where she could only communicate with these people. Why would I do that for her if that wasn't an absolute necessity? And that was our for sure deciding factor, not that we were ever really going back and forth.

Some parents described uncomfortable social situations where talking to parents of hearing children resulted in unwanted pity or concern for their situation. Eric, Rob and Chris shared how encounters with hearing individuals, in which sympathies were offered made them uncomfortable. Chris shared how he sometimes worried about telling people about his son's hearing loss because he was concerned that other people would be upset. Rob shared an experience that was perhaps indicative of heightened sensitivity and responsibility to a stranger's reaction. He described feeling the need to overcompensate for what he perceived as other people's sad reactions. Even as he acknowledged that people's preconceptions about hearing loss were uncomfortable for him, he also wondered how it would affect his son.

Rob: There was a 12-13 yrs old hanging out in the park and Wyatt was there rocking out in his little hat and I guess she was able to see the hearing aids underneath. And she says to her friend, "Ohhh the baby is deaf." I was trying to work this out. Do I make her feel better about this or do I let her be? I am a social person and I want to make sure that everyone is getting along okay and those preconceptions make a ripple and it is very uncomfortable for me. I don't know what it is going to do to Wyatt. Is he going to be adversely, is he going to take that wrong or what?

Eric shared an experience about a social encounter that differed from the previously described experiences of isolation. The following statement reflected his feeling of being isolated from other parents about regular aspects of parenthood when assumptions were made about how he viewed his son's hearing loss, i.e. when people assumed it was a "tragic experience".

Eric: I remember having this guy, he's a parent and a really nice guy, and we were talking about daycare. And I said, yeah you know we are really trying to find the right daycare. They have to be able to deal with the CI's and I could kind of see in his face he was kind of looking at me like, "Oh wow I'm really sorry that you have to deal with that", and I wasn't feeling that. I was just talking about what the reality is.

Some parents also shared how they isolated themselves from certain aspects of hearing loss by limiting the amount of information that they gathered. Rachael needed to limit the information that she gathered because it threatened to deepen her sadness and might ultimately not apply to her child. Val shared her thoughts about being involved or connected to individuals or activities related to hearing loss; it was not something she prioritized.

Val: I feel that a lot of people who have kids with these issues pretty soon the child and the whole family is defined by that and they socialize with only those people or it just becomes so much a part of them. I know it's a lot of his life, it's part of him, his deafness but again he's a hearing child now. He is a hearing and he is a deaf child now – with them off he's deaf with them on he's hearing. And so I just didn't want to be talking about deafness 24/7 in our house and I didn't want him to be surrounded...

A number of parents also shared how instead of turning to other parents, they turned to the Internet for information and support. Even to connect to other families with whom they could relate. Both Val and Claire had connected with online chat groups of families of children with cochlear implants. Hannah shared how she followed the blog of other children's progress. Elizabeth talked about long late night searches on the Internet. Some of these parents did this in conjunction with seeking person-to-person support, whereas for other parents it was their only source of contact with other parents.

Another potential reason parents may have chosen to isolate themselves from other parents of children with hearing loss was the need to avoid dealing with the “conflicting”, “political”, and “cultural war” reflected in the information provided. Four of the mothers and two of the fathers spoke of how they tried to avoid those unhelpful and difficult to navigate situations wherein they were put into positions where they felt

they received conflicting information, misinformation or had their decisions judged. Parents shared having these experiences with professionals representing all the divergent philosophies. Zoe described her struggles with wanting her son to know other children with cochlear implants but also feeling that she should avoid environments where there was the potential that signed language might be used. She described an experience that angered her, whereby she felt like she was misinformed.

Zoe: They had this lovely little flyer and I was like okay I'll go. [Our therapist] told us that if he's getting implants she doesn't want him using sign so I was right off the bat, no we can't go there because they use sign. So I didn't go there up until just recently he started going there. But I knew about it all along. I just didn't take advantage of it but I also thought they weren't going to be accepting of the CI route but I wish I kind of knew they were open because I would have been a lot more ready to go. So I really wish they kind of almost advertised that...

Only three other mothers in this study did not express sentiments that reflected a desire to isolate themselves from other parents with children with hearing loss. In fact two mothers, Claire and Elizabeth described opposite experiences where they actively sought out connections with other parents, and even considered starting their own chapter of a parent support group. Christina did join a parent group explaining how she was looking for reassurances in the successes of other children. Adam shared how he did not remember reaching out to other parents but rather having parents reach out to him.

Adam: I don't remember getting connected with a lot of other parents to talk about Parker because again we moved so fast forward. But I know we have had other parents call us, so people have referred us to people to talk to and so we are always happy to talk to anybody about that and go on about how happy we are with our experience. So that's what I can remember, is us taking on inbound calls rather than making outbound calls.

Many parents expressed their desire to isolate themselves from other families of children with hearing loss for various reasons but there were painful experiences tied to

those many decisions. Perhaps as the parents in this study became less aware of their child's hearing loss, social encounters that reminded them of the hearing loss, potential differences, or challenges caused emotions to resurface that perhaps had not been previously processed. The avoidance of potentially painful situations might be one way in which parents processed their grief. But in doing so there was the potential that they cut themselves off from knowledge that might break down feelings of isolation. The value in connecting with other parents for the purpose of giving and receiving mutual understandings or finding the "ordinary" in their experiences did not appear to be perceived by the parents. Instead they shared how they were wounded by these types of encounters.

Brought back to grief.

As previously discussed there was a strong trend towards families demonstrating a return to a sense of "normal" after their initial reaction to the diagnosis. Yet even though families shared their perception of their child as normal, they described being deeply saddened when they faced situations where they could no longer hold that belief to be true. These discrepancies occurred when issues around communication difficulties surfaced. Mothers spoke about how in those instances they felt grief, although not as intensely as when their child was first diagnosed. Still they returned to those initial feelings. Three of the mothers whose children were amongst the oldest of this study shared situations wherein communication was impacted because of the limitations of their child's equipment. Situations that surprised parents concerned sports, swimming or bedtimes. These were the times that their children's technology could not be accessed.

Val found herself really surprised to be feeling that way again because she viewed her son as “hearing” and the situation reminded her that, in reality, he was not.

Val: We just see him as hearing now and then all of a sudden here’s something we just thought we be okay and it’s just really hard, it’s really hard... I just felt helpless all of a sudden. It’s like oh my God, he can’t understand me, he’s not doing what he is supposed to be doing.

In the following quote, when asked to identify her feelings, Julia named them as “minor grief”. She described feeling frustrated in trying to communicate with her child when the cochlear implants were out, like at bedtime or when it came to discipline. She continued to relate how she was starting to think that her son might be limited in the activities in which he participated. These provoked feelings of a loss for the life she had envisioned for her son relating to and participating with his peer group. This quote is in stark contrast to her previously shared sentiments of acceptance.

Julia: It goes to that not fitting in. He can’t play hockey or he can’t play soccer when all his other friends are doing that, that’s going to concern me. I think right now that he is going to be limited in what he can do and that sort of brings me back to that the part of worrying about your child. Swimming lessons is another thing..., it’s the loss of the life you had envisioned versus the one you get. His life will be fine if he can’t play hockey - it’s what that symbolizes for him, the fitting in with all your friends. It’s more sadness for that not the actual not playing hockey.

Similarly, Rachael shared a return to her initial feelings of grief when she allowed herself to think about the ways in which her son’s life would be impacted because of his hearing loss, in terms beyond speech and hearing.

Rachael: There are routinely times when I am brought back to earth, not as devastating as when we got the diagnosis. Kids will be out playing street hockey because their parents have been able to train them to keep an ear and an eye out for cars and my son is standing on the sidewalk watching. He wants to play in the street and I am not letting him play in the street. My husband and I bicycle everywhere. At what age will he be able to bicycle everywhere? Will he ever be

able to ride a motorcycle? Yes he will be able to speak and read and write and go to college and yadayadayada, but there are other things in life too, and every now and then I sort of think of these things and it's just kind of like a you know, cold water.

Chris continued to have some difficulty in labeling his emotions when asked about a return to some of his initial feelings of grief. He described having to yell in order for his son to hear him and how that reminded him that he was hard of hearing. This awareness was in opposition to the way he describes his son's hearing loss saying he does not identify him with his hearing loss. He was also quick to attribute his having to yell to being no different than other hearing children.

Chris: Sometimes when he is doing something and I have to get his attention, I have to yell. But that is one place where I do sort of have... I don't like to yell because that does remind me of his situation especially when he doesn't have his hearing aids in and he doesn't hear or that he is not paying attention you never know.

Previous discussions, revealed an awareness of potential challenges that their children could face and the ways in which these challenges renewed expressions of grief. These descriptions were different in that there was an element of pain associated with the revelations. Not only did parents indicate that they grieved when issues surrounding communication surfaced, but parents also described being saddened as a result of issues surrounding technology or their child's potential vulnerabilities as they gained life experiences. A number of parents—Rob, Julia, Val and Rachael—shared their sadness when reflecting the obscure potential that their child's technology, like for example batteries, might cease to be available. Other parents talked about the sadness that they felt when they thought about their child being vulnerable or dependent on others as they aged

and got married. Claire acknowledged her devastation in thinking about the day that her son's hearing loss would be targeted for ridicule.

Claire: The day he comes home and he's upset and he says someone has made fun of his hearing - that's going to kill me. That's absolutely going to kill me, like you can make fun of absolutely anything but not that- you can make fun of his race, of the fact that he has funny hair but on the deafness, no...

Anger was another emotion that some parents experienced as a part of their ongoing grief process. For Zoe, anger was a recurring emotion. Zoe explained she sometimes felt angry in situations where she compared her child to other younger children.

Zoe: Our anger is not towards Lucas but towards the deafness. My brother had a child 6 months earlier than us so they are very close in age, so of course he does everything perfectly. I would get this insane anger in me. That brought out a lot of anger. Even now at work there are people just getting back from mat leave and their children aren't even one and they are like, well she's already talking and I'm like right...I'm angry and I feel it is unfair.

Zoe also shared her anger about the high expectations for her role as a parent especially when there were differences in how that role was viewed.

Zoe: I love [our therapist] but she gets a little bit stern with us when he can't sit for an hour straight and he's 18 months old. And she's like, yup ADD, and I was like listen he's a young kid, leave him alone. She feels like you have to be really stern with him and I don't necessarily believe in that but she's like, well he's not going to listen to you and you're going to screw up his chances to learn to the optimal level cause he's going to be too busy having temper tantrums. And I'm like that's how babies develop. You know so that, I find that for such a little guy with so many delays, a lot is expected out of him and I get angry for that too.

All of the parents in this study shared feelings and thoughts about moving forward over time with experience; they also shared moments of sadness brought on by certain experiences or reflected in the way they discussed certain situations and feelings. In

talking about changes in thoughts and feelings over time, both Hannah and Elizabeth spoke about the notion of living with paradox. Hannah shared an experience where they met another couple with a child with cochlear implants who shared that they were happy their son was deaf and would pick it again for him if they had to do it all over again. Hannah articulated her paradox indicating that while she loved her child for exactly who she was and attributed who she was to her experiences with cochlear implants, she emphatically stated that if she could chose, she would not want her daughter to be born deaf.

Hannah: I love [my daughter] for who she is, the implants don't even bother me, like I think they are cool and cute. But if someone said to me, okay today if I could snap my fingers and she wouldn't be deaf, I would say sure definitely, like you know for sure. Maybe I am just not there yet, maybe I will be in a few years it's only been two years. I wouldn't change who she is but I would still snap my finger in a second because her life is going to be harder. I might get to the point where I might say if I could do it all again I would chose these same for her to be born deaf but I am not there yet.

Elizabeth also acknowledged that she lives with paradox in terms of her emotions surrounding her son's hearing loss. Some days she was able to take it all in stride, feeling like the loss is "inconsequential" and on other days she continued to wonder why or she started to worry how he compared to other children.

Elizabeth: I go up and down. Some days it is just one more thing like you know whatever. It's funny even when he first got the hearing aids, some mornings it was like, ah it's just one more thing to remember to bring in the diaper bag or whatever else and then there are other days when it's like, why us, why? why?

Summary.

The major trend in parents' continued expressions of grief was their struggle between their attempts to view their child as "not deaf" or "normal" like a hearing child and those situations where they could not reconcile those visions with the realities. To

view their children as not impacted by their hearing loss, parents, especially the mothers described feeling a great deal of pressure to carry out therapy. Parents also described how social encounters contributed to feelings of grief when aspects of their child were revealed to them in these interactions, emphasizing their differences.

Theme 3: Being Cared for Emotionally.

Another major theme of this study concerned the parents' perceptions of being cared for emotionally. Parents shared their perceptions about being emotionally cared for by each other and by various professionals who were involved in their care. They shared their thoughts about being supported following the diagnosis, what qualities they found the most important for their supporters to have and how the type of support impacted them. The parents also shared experiences about how they had been willing to accept substandard care from professionals. For many parents emotional support equated informational support and action. The most common need that parents spoke of was the need for them to be reassured and to be offered the hope of a normal future for their child.

Initial Support.

Parents shared their perceptions about receiving little emotional support from professionals when it came to processing their child's initial diagnosis. Claire, Adam and Derek explained that they felt it was the job of family, friends and each other to look after any of their emotional needs. Claire and Eric both expressed feelings that they could have used more emotional support throughout the process of "going through diagnosis and dealing with the huge amount of information that you had to go through". Both Claire

and Eric explained needing to go home from the initial diagnosis and Google “cochlear implants” to gain an understanding of what it was.

Other parents spoke about the significance of a knowledgeable touchstone person available to them who was able to answer questions and who was personable. Two fathers admitted that they did not understand the purpose of being connected to a support professional. As previously discussed, their preference was to proceed with speed to an intervention program. Derek explained how he felt about the initial support that was offered to him.

Derek: For me, I didn't see the point...like for me, we were okay and I was okay and I don't know if that's the role she was trying to play like in case we needed somebody to cry out to, or whatever. But I didn't really get anything out of it, maybe other people feel differently.

Parents also commented on the number of brochures and large manuals presented as an overwhelming experience that was ultimately not the most helpful. Parents—Elizabeth, Val and Claire—admitted that they put everything away in a drawer and never looked at any of it. Claire's following statements reflected her feelings about how her initial support did not work for her.

Claire: I don't know how the best delivery would have been because to have just been given a manual and here is your deaf child, here are your choices... that's not it. And brochures don't work and being talked to really fast, that doesn't work. I don't remember half the things we were told.

Hannah shared how it was difficult for her to talk with anyone immediately following the diagnosis because she was not aware of what information she should ask. Two other parents, Val and Julia, made statements that reflected their need for a supporter in the earliest stages of processing their diagnosis to be balanced in terms of

providing hopeful messages about the future while acknowledging the parents' emotions at that moment and time.

Val: I didn't want friendly around me at that time - I just wanted somebody who understood me and just didn't want a happy go lucky person around me at that moment.

Qualities of supporting professionals.

Many parents felt emotionally supported by always being given answers to their questions and being connected to professionals who were available and able to answer those questions. The answers that parents found the most helpful were those that were positive and those that specifically gave parents some reassurance about their child's prognosis. "Confidence" in the reassurances given about positive prognosis was commented on by many parents. Adam explained his appreciation for this confidence received from the professionals.

Adam: The biggest characteristic I was set on emotionally is confidence. Everyone that we dealt with approached us with "oh this is going to work". Like there's not, this might work, we'll try this, no wishy-washy. Any time that it had to get a little wishy washy was just, you know it is their job to impart some sense of the fact that there is some risks, like, we kind of have to say it might not work but it will.

There was also the notion among the parents that the professionals were the experts and were therefore able to make those guarantees about progress. Julia and Derek valued that "expert" reassurance. If an expert told Julia there was nothing to worry about, she would not be worried.

Julia: When someone seems to be an expert you're like okay, you're good. They tell you okay here are the next steps, here's what we're going to do, it's going to be fine, your kid is going to be fine. I love those people. I wanted to be surrounded by people who said, oh this is fine, a bump in the road, so that's how they were.

Derek's following statement is indicative of both the sentiments that Adam and Julia shared in viewing the professionals as the experts with solutions and they felt confident that positive outcomes would be achieved. There was a strong sense that parents made their decisions based on these types of feelings.

Derek: It was reassuring. I felt confident that there was a solution and this person knew what they were talking about and there to help us through...she was an expert helping us and I felt like we had an expert. It wasn't somebody who was like this may or may not work.

Chris's sentiment was similar to Derek's in that it reflected the notion that solutions, proposed by professionals with a great deal of experience, were soothing.

Chris: The fact that this was not considered exceptional, wrong or something to be worried about. That it was just okay here's what you do, that is more soothing. To know it is not the end of the world. It is not a major problem, that it is not even a huge problem, it is something that can be dealt with and we know how and we do it all the time.

Parents also shared how attending appointments was a helpful part to their processing of grief. As Julia explained, being told weekly that her son was making progress she felt was emotionally supportive.

Julia: Once a week having someone telling you how smart and well your child was doing was so emotionally supportive. If it wasn't for that I think I would have freaked out a lot more - once a week someone told me everything was okay.

Christina shared her appreciation for the support that she received from professionals who made her feel like her child was normal, especially when she struggled with the notion.

Christina: What came to my mind, it's not really a quality, but making it seem normal you know. Like you just felt like obviously my kid isn't like that but it felt good to go to the appointments. I kind of looked forward to them.

Eric's statement was different from those parents who expressed valuing confidence. For Eric a supportive professional was someone who saw his son first as a capable child and the hearing loss as secondary. What was similar to the experience of other parents was also valuing professionals who did not approach hearing loss as a tragedy.

Eric: Positive professionals are not looking at [my son's hearing loss] as a tragedy, quite the opposite they look at your child and say there's a great beautiful child, let's get to work.

When professionals showed genuine care and engagement with their child, the parents felt significant support. Parents appreciated professionals who were flexible to their child's needs and sensitive to their temperaments. Elizabeth shared how much it meant to her that their therapist demonstrated these traits.

Elizabeth: [Our therapist] is so wonderful and so caring and is willing to do whatever. The first time that Wyatt didn't want to sit down she was like okay no more sitting down and we're on the floor. We all take off our shoes and we're all crawling around on the floor. She goes with the flow, she works with him and she is so good with children.

Both Elizabeth and Val also shared how much it meant to them that their therapist genuinely cared for their children. Val explained how she even came to feel that their son's therapist has become a part of their family.

Many of the mothers and a few of the fathers explained that they did not want to have to deal with other people's opinions or get involved in the political climate of communication philosophies, in terms of what communication method was best for their child. As Hannah stated, "you just don't need drama when you are trying to deal with this." Two of the parents, who struggled in getting both spoken and signed language

support, were grateful and appreciative of being connected to supporters who were non judgmental and open. Claire described how she had to navigate the different professional agendas and also how meaningful it was for her to have found one professional to whom she could speak her mind.

Claire: With different professionals you always feel like they have this agenda. They have this idea of what will work for your child and there have been times when I feel like I couldn't say what I thought or I couldn't ask my question because I knew right away what their answer would be, because I knew this person is pro cochlear implant or no sign or this or that. Our therapist was never like that. Almost every week I go there and I think, thank God. She's the only one where I can just say what is on my mind and not have to worry about what they are going to think or that they are not going to like me and they are going to bump me.

Rob also shared how much he appreciated that type of professional.

Rob: Having a non partisan educator is so great to be able to see and ask our questions and it is really inspiring.

While most parents very clearly articulated what qualities they knew they wanted and appreciated in terms of being supported, parents also articulated what they found unhelpful. Husband and wife, Adam and Julia, both described the importance of confidence; they shared experiences in which they encountered professionals who did not provide them with the same reassurances. Adam explained about not wanting to get involved with individuals who “appeared to be more trying to prepare us for a different world, a world more if the cochlear implants didn't work or if he had reacted differently”. Julia also shared how the very first messages that she received about hearing loss were the one's that she found the most depressing.

Julia: The first message I got from them was the reality of the deafness is that these are the things that are going to be different... your child is going to have this... I was told that this would be the worst year of your life or something like that and that makes you go oh this must be awful, she is an expert and she knows.

So my first exposure was towards this really negative group that was sort of how I felt. Oh okay well this is going to be something that really ruins our lives and that's fine we'll deal with it but it's not going to be as good as we hoped.

Christina also explained that both she and her husband felt they were looking for messages of reassurance that they did not receive.

Christina: Cause we didn't get a lot of that, I think you were saying, you got a lot of oh it was fine, we didn't get that so much. Like I think we were kind of looking for a, it's going to be alright in a couple of years he's going to do this or he's going to do that and we just didn't, people would say well this is the loss and this should happen but it's unknown and so I think we were kind of looking for some more.

Two other parents shared how when professionals shared information about successful Deaf professionals they did not find that information to be reassuring. When being informed of intervention options, Rachael, was made aware of a Deaf professor in a Deaf Studies program. Instead of finding comfort in this information found it became a reminder of the ways in which her child might be limited in what he could accomplish.

Accepting less.

While parents could clearly articulate qualities of good support, in other situations parents were willing to accept substantially less. In some circumstances parents excused intellectual bullying and poor interpersonal skills. Seven parents shared their fears of being open with various professionals about their sadness, anger, or uncertainty or about their own developing communication philosophy. They feared it might in some way affect the service that their child received. This is reflected in Elizabeth's description of working with a professional who had a different communication philosophy than the one she was developing and her struggle with feeling like she just had to accept it.

Elizabeth: I remember having this constant debate with Rob about how I hate [our therapist]. I hate, hate, hated her and it's like but I feel because you are also in this position where you can't criticize this person because this person is in charge of teaching your baby to speak and you're going to be seeing this person possible every week for the next six years so you can't - you don't want to pick a fight with this person.

Other parents also shared feelings about being unable to address concerns or voice criticisms to those professionals who were involved in the cochlear implant process. As one mother put it, "they hold the key and if I piss them off" their child will suffer. Claire's statement reflected feeling disempowered in a situation where she obviously felt like someone else held all the power.

Claire: I didn't know what to say because this is the person that is getting your child to hear so you don't want to say anything.

Supporting each other.

In terms of the way husbands and wives described supporting each other: each described having their needs met by their spouses at first mention. Fathers were more specific about how they felt they met their wives' needs, in part because they described a large part of how they grieved as related to the provision of that support. Wives made more general statements, indicating that they were there for their husbands and hoped their husbands would say the same about the situation. Husbands were also less specific in indicating how they felt supported by their wives. This resulted in the sense that parents did the initial processing of grief on their own. Claire and Zoe explicitly shared how they felt the need to process their grief on their own and were given that space. Claire's husband Eric on the other hand felt he needed to be surrounded by friends to process his profound reaction. Once he felt that task was accomplished, he indicated that perhaps he became no longer emotionally sensitive to his wife's needs.

Eric: My wife gave me a lot more support initially than I gave her. She probably has not had as much support from me in that once I accepted it I moved on. I was on it and everything and if she was having moments of vulnerability or feeling emotionally charged about things maybe I was not noticing or not picking up on those things.

Jason also explained that he felt like perhaps he relied more on his wife for support and was possibly not there for her in the same way.

In all but two families, the mothers were the only ones who took their children to therapy sessions. Even though many mothers commented on the pressures that they felt as a result of the demands of therapy, they did not share any resentment towards their husbands or seem to begrudge having to take on this responsibility. Derek and Eric shared feeling some guilt for not being able to attend all appointments. Derek's wife Christina shared some initial tensions she experienced in always trying to describe to her husband what was done during therapy appointments, which they later resolved. Eric's wife Claire shared how her husband felt as a result of not being as involved because of having to work.

Claire: He needed support because he was back at work and all this stuff was going on. He wanted to be there for all the appointments. He always says it is a different kind of hard for fathers because we want to live it and we don't really live it. He sees it as another factor that makes my son and I closer because we go to all the appointments together and he doesn't get to- he goes to AVT once a week...

A coming together of the parents was revealed when they shared the ways in which they navigated the decisions in front of them. Many parents talked about the sense of teamwork, how they felt like they were, "attacking issues the same way" or "would come to the same decisions in the end". Zoe and Adam also talked about support from extended family. Adam commented on how wonderful it was that the entire family was

on the same page and Zoe shared how difficult it was for her when some extended family members attempted to minimize her concerns. The following statement made by Hannah and Eric demonstrated the feeling of togetherness shared by most couples.

Hannah: We are both very lucky that we both felt the same because we are actually very different. We could have, you know you could have had someone who did not have the same needs as you or wanted the same things as you. You never know until you face the challenge and we were lucky that we were always on the same page and that made that aspect of it a lot easier as well.

Summary.

The support needs of parents were varied although there was a trend among them to value strongly those professionals who would provide parents with reassurances about prognosis. Professionals were valued as the experts above all else. Parents also shared how meaningful it was for them to have professionals who showed a genuine interest in their child; that reassurance provided them strength and a greater sense of wellbeing. Such varied needs among individual parent participants made it difficult to derive conclusions about general differences between husbands and wives, especially in terms of support needs. One exception emerged: husbands in general were a little less clear about what their needs were and rather emphasized their role in supporting their wives.

Conclusion

The themes and their subsequent subthemes were supported by numerous quotes drawn from the focus group discussions with the participants. Three central themes emerged from the analysis of this qualitative data of parents' perceptions of grief in the context of an EHDI program. The first theme focused on parents' feelings of grief at the time of the initial diagnosis. The grief parents experienced was related to their

perceptions of a variety of perceived losses that came with the diagnosis of hearing loss. The second theme explored the ways in which paradoxes were revealed as parents processed their grief. Parents expressed contradictory emotions of both joy and grief; they attempted to move forward and away from grief, even as they described experiences of staying in place. The third theme described parents' experiences of being emotionally supported in the context of EHDI programs. As part of EHDI programs, the role of the family support worker was discussed among the parents with varying degrees of acceptance. Parents also shared the positive ways in which they were supported and attempted to support their life partner.

Literature indicated that perhaps in the context of EHDI, the grief experience would be different for parents. Grief would be less complicated as a result of the diagnosis occurring in the newborn period. The data from this study was not indicative of less complicated grief. The data suggested that grief was not a linear process with an end point signaling completion although many of the parents appeared to have the desire to portray that message. The data also suggests that the term "chronic sorrow" was far too negative and did not fit with the experience of these parents who worked so hard to normalize their child's hearing loss. The data also revealed that grief can be confusing and contradictory. In addition the data provided insight into the role that professionals played in helping parents to understand and experience their feelings in the situation. The potential implications of this experience of grief and support will be discussed in the final chapter.

Chapter 6 - Discussion

The purpose of this qualitative research study was to gain an understanding of parental grief experiences within the context of an early hearing detection and intervention program and to examine parents' perception of the professional support they received. This chapter will discuss how parents described their experience of grief and the paradox that revealed itself as parents shared feeling both joy and grief concurrently. This chapter will also address the ways in which parents built their meaning of deafness and the implications that resulted for support professionals who play a role in how that meaning is built. This chapter will conclude with a brief look at the limitations and needs for further research.

Grief in the Context of EHDI

As part of the design of this study, in the discussion about grief with the parent participants, parents were not provided with a framework in which to discuss their grief. This lack of structure provided parents with the control and freedom to explore the meaning of their own experiences without adhering to patterns in previously articulated emotional journey, grieving was expressed for a variety of losses perceived by them. Many mothers described sadness for the loss of the anticipated role of motherhood; other parents also shared feeling sadness for the loss of what they had envisioned for their child. But parents also wanted it known that they felt joy, they felt as though they had overcome the sadness even though they also shared its recurrence, albeit rarely.

In chapter two, different perspectives on grief were introduced. Three specific grief theories were described. The first was stage-based models similar to that of Kubler-Ross (1969) grief model that described grief as time bound, involving a series of stages

with a final phase of acceptance. The second theory—chronic sorrow—was described as a reaction to ongoing loss wherein some sadness was always present in the lives of the parents of children with disabilities. The third concept explored those theories that talked about joy and grief, positive and negative appraisals, and the feeling of many different concurrent emotions.

Therefore in considering the grief theories explored, the emotional journey of parents in no way reflected a linear experience. And while parents talked about acceptance, the exact meaning that parents attributed to that word appeared unclear even to them. Regardless, the talk about acceptance did not equate an end to the feelings of grief. While the theory of chronic sorrow encompasses feeling a range of emotions throughout the course of time triggered by various event, which was described by some of the parents in this study, it is far too negative a label for their shared experiences. The grief experience shared in no way appeared more easily resolved as a result of early identification. In fact, similar to Young and Tattersall's (2007) findings, the grief experience was perhaps even more complicated as a result of the diagnosis occurring the EHDI context. The emotional journey of the parents in this study was paradoxical and will be described further in the following section.

Explaining the Paradox

While parents were open about grief feelings immediately following their child's diagnosis, they indicated that the grief was short lived. This is contradictory to research which indicates that the processing of grief takes time. Parents in this study shared prioritizing information and action, which once carried out enabled them to feel joy and positivity. The positivity and joy that parents shared had a great deal to do with their

personal interactions with their children, similar to the findings of Kearney and Griffin (2001). Parents shared how their love for their child surpassed negative feelings. They also shared how joyous they felt whenever their children were successful. Most often that success was measured in speech and hearing terms. Considering that most of the children in this study appeared to have age appropriate language skills, a connection could be made about the reason why these parents were so positive. Their children were doing well with the technology which rid parents of the grief they initially described over their perceived losses. This implied that parents ceased to view their child's hearing loss as limiting because they came to see their child as a hearing child.

Yet there were some of the parents who did not articulate specific joyous situations the way other parents did, not perhaps because they did not feel joyously about their child, but because their joy was experienced in other ways. Parents like Zoe and Derek, who had the shortest time span from their children's diagnosis to participation in the focus group, seemed to be in a different place in their grieving process than some of the others. For these two families there was a strong focus on waiting for their child's speech to develop, which may have been indicative of why they did not share similar sentiments to the rest of the parents about celebrating their child's successes.

As part of the parents' overall messages of positivity, parents also shared many "positive illusions", a term used by Taylor and Brown (1988) to explain how parents of children with a disability can demonstrate positive evaluations of their life's circumstances. This can provide parents with a perception of control and a sense of optimism. Many parents in this study made the comment that they felt their children were not as badly off as others and again highlighted many of the speech and hearing successes

of their child. Zoe shared feeling reassured about her own abilities to do appropriate speech therapy with her son, especially when she compared her family's situation to similar families who have English as a second language. Rachael described being grateful that her son did not have a cognitive disability. She explained feeling as though she had "won the birth defect lottery". In terms of taking control of their situation, they aimed to erase or lessen the initially presumed challenges their children would face as a result of their hearing loss. Parents genuinely felt as though they had done everything in their power to make sure that their child was provided with every opportunity. This sentiment was expressed by many of the parents and was strongly exemplified in Val's statement.

Val: I can't tell my son 18 years down the road that I didn't do everything I could based on the technology that was made available to me to give him the best possible life and the most options I have done the best that I could do ...

Through the data analysis an interesting theme evolved: despite the projection of many messages of positivity and joy, at times parents' choices of words and other shared experiences reflected continued expressions of loss, sadness or grief; however, this message was often difficult to decipher. Consideration and comparison of parental narratives revealed concurrent experiences, contrary to the joyous ones, that caused parents to feel emotions connected to grief. Research findings have presented factors that are indicative of where individuals are in their grief processing. Identified factors indicative of ongoing grieving are not limited to but include: 1) continuing to search for a cause, 2) having difficulty balancing the demands of life, 3) continuing to be emotionally connected, or angry, by the events of the initial diagnosis, 4) demonstrating constant vulnerability throughout hypersensitivity, temper and an inability to cope with criticism of oneself and one's child (Marvin & Pianta, 1996; Carpenter, 1997). Parents in this

study demonstrated their continued grieving through these expressions. Confusing and contradictory experiences and feelings expressed by parents required consideration and comparison to decipher the range of their emotional journey. What became evident was that these parents held two contradictory thoughts and feelings. But for the most part, parents appeared uncomfortable or unwilling to acknowledge that these paradoxes existed within themselves. While parents shared and projected messages of positivity and joy, grief continued to be a recurring experience for them in the following ways. Parents described their ongoing search for a cause of their child's hearing loss and a continued sense of blame for its occurrence. Parents also shared experiences that appeared to reflect their difficulty in balancing all of the demands of life and of having a child who required so many medical appointments. Almost all of the parents vividly remembered the events surrounding their child's diagnosis. Some parents focused anger on the professionals imparting that news; other described encounters with strangers in great detail that contributed to their grief.

Researchers have identified different ways in which grief is not resolved or becomes dysfunctional, or simply put, is ongoing. Parents shared some experiences that suggested continued grieving but there was reluctance by parents to acknowledge it as such. Some of the parents in this study continued to search for the cause of their child's hearing loss. Parents, like Claire and Derek explained that in their search they continued to blame themselves for their child's hearing loss. Claire described longing for a release from the heavy weight of blame. Jason explained even once he found out the cause, he continued to blame himself. Parents shared experiences that reflected a struggle to find a balance in relating to their child simply as their child while they helped their children

develop the perceived essential speech skills. Balancing the demands of life with the demands of parenting a child with a disability have also been identified in the literature as a way to determine if parents are processing their grief. While parents shared how normalized their life had become, they also described the extreme pressure that they felt as a result of their intense focus on their child's speech therapy. Elizabeth expressed her difficulty in balancing her own life. Her difficulty was in finding babysitting services to go out socially when all her "babysitting goodwill" was being used up for hearing loss related activities (signed language classes).

While there were obviously profound changes in thoughts and feelings throughout the course of time, parents were still able to relive the moments of their child's diagnosis as if it had just happened. Regardless of the length of time that it had been from the initial diagnosis (the time span between diagnosis and the time of these focus groups ranged from 9 months to 45 months), most of the parents, especially the mothers, reflected back and remembered vivid details of the events of the initial diagnosis. Parents seemed less willing to connect with the emotions surrounding that time frame, preferring to focus on step by step events, only sharing their initial grief after a great deal of prompting. They all specifically recounted words spoken to them by professionals and even in encounters with strangers, especially when those things were unhelpful and hurtful. In one case Val described feeling like she was being told that her son was dying. Parents admitted how they felt as if they were not being given the answers to their questions at the time of diagnosis. Jason recalled an interaction where a stranger's comment drove home how sad he was feeling. Parents seemed to want to quickly distance themselves from these initial negative interaction and feelings.

The parents in this study appeared less willing or aware that subsequent emotional responses, after the initial diagnosis, were connected to ongoing grief. Perhaps, as the literature indicates, parents do not recognize their emotions as reflecting a grieving process because no physical loss has manifested. Yet the perceived losses experienced, the changes to their lives, and the lack of understanding they encounter for however they are feeling, contribute to overwhelming emotions and guilt (Holland, 1996). For the parents of this study, their intense focus on moving forward and the positive age-appropriate speech gains made by their children has perhaps led them to feel as though there was nothing to grieve. In some ways this belief might have prevented them from exploring all aspects of hearing loss and its multiple meanings. But the literature also indicated that it can take years for parents of a child with a disability to recognize the extent of their perceived loss or their recurring grief (Roos, 2009). These families are still in the early years of a lifetime of experiences and grief has the potential of resurfacing as other stressors present themselves, for example, when their children enter the education system (Meinzen-Derr, Lim, Choo, Buyniskis, & Wiley, 2008). An action orientated approach to processing grief is not in itself an inappropriate way to grieve. Most parents in the current study employed those types of strategies. Nor is it inappropriate to at times confront grief and at other times avoid it as outlined in the dual process model (Stroebe & Schut, 1999). Parents like Hannah, were busy “doing” and as Christina stated, “not dwelling” on their feelings. Or like Julia and Chris stated, they have just “accepted it”. Or like Val and Adam, who are able to sometimes forget that their children are deaf. It’s significant to note that these parents did not see the need for any other type of processing.

Yet there is a healthy component to processing grief and potentially negative consequences to resisting it (Moses, 1987).

Larson (1998) reported on how the judgment of family members is called into question by professionals when parents are overly or unrealistically positive. This represented a failure on the part of professionals to understand the impact of a child's disability on the family. That was not the intention of this discussion nor was it intended to pass judgment on the ways in which these parent participants navigated and processed their grief on learning about their child's hearing loss. Grief was a personal experience. The parents in this study grieved and processed their grief in common ways and in the best way that they personally could, given the knowledge they had garnered and the personal resources that they possessed. They expressed positivity and were less comfortable in moments of grief, despite shared experiences that reflected some elements of continued grieving.

Building the meaning of Deafness

When considering how these parents came to build their meaning of deafness, another interesting paradox evolved. Parents wanted to portray complete acceptance for their child as she or he is, at the same time they expressed sentiments reflecting a complete lack of acknowledgment that their child's hearing loss makes them fundamentally unique. It was paradoxical for parents to talk about accepting their child's hearing loss while suggesting that the implant had fixed their child's deafness. It was also paradoxical for parents to share how dealing with their child's hearing loss had normalized him or her, but that normal was narrowly defined in terms of "normal hearing children". These findings are very similar to the work of Young and Tattersall (2007).

Parents shared initial descriptions that painted a very negative view of their initial meaning of deafness. Hearing loss was viewed as a limitation, loss of opportunity and lifelong dependency. Parents initially presumed that American Sign Language was their only option and accepted it with resignation and fear. Many parents wanted limited exposure to Deaf Culture and to other children with hearing loss. These experiences are contrary to those described by Wainscott's (2010) parental perspective study wherein parents indicated that their interactions with Deaf adults and perceptions of Deaf Culture were positively influential on their decision making. While the importance of these types of relationships are highlighted in literature (Hintermair, 2006), encounters and meetings with Deaf professionals, parents or mentors did not alter held negative perceptions of the parents in this study. The next step to building their meaning of deafness that was common amongst the parents was the belief that technology can overcome those negative implications. Holding this belief signified the notion that their children can be returned to normal, "the new normal". Many parents credited cochlear implants as magic cures responsible for taking away their child's deafness, Val even shared how they referred to the implants as her child's "magic ears". Julia clearly articulated how she came to see her son as no different from other people "having a perfect life, the only difference is that they wear equipment". Rachael and Chris often made the analogy that the solution for their child's hearing loss was hearing aids like glasses are the solution for people with vision problems. Val often emphasized her gratefulness for the technology and how knowing her child was a CI candidate meant he would have the ability to "assimilate quite well into society."

Val: I have to say it is like a Christmas gift every day when he turns his head. I will never get over that feeling. It is a brand new gift everyday and it makes me

want to cry when he turns his head and I just think, oh my God it's incredible! Twenty years ago he would have gone away to a special school and I am just unbelievably grateful for technology.

While the technology was credited for the “new normal”, normal was defined by parents only in the parameters of speech and hearing. Parents saw their children as no different than any other child based solely on speech and hearing. Missing from their meaning of deafness is what *actually* might be normal for their child. As a result parents struggled with how to identify their child, “deaf” or “not deaf”. This was evidenced by Claire who voiced an awareness of her son’s identity as a Deaf individual. Yet when she explained how her decision to expose her son to signed language within the context of what hearing/normal parents do, rather than what her son needs or has a right to, she revealed a paradox.

Claire: I am treating him like a hearing child. All my hearing friends did baby sign with their kids and I don’t see why I couldn’t do the same. If [hearing professionals] says the input is so easy, isn’t the access to sound the same for them at that age?

Without a broader definition of deafness, i.e. beyond parameters of speech and hearing, parents demonstrated a limited awareness of the ways in which their children’s future might be impacted by their hearing loss. As a result what was also missing was a discussion regarding parental preparedness for how they might handle those experiences. For example Claire shared how devastated she was going to be if anyone ever made fun of her child’s hearing loss as opposed to acknowledging that it would happen and focusing on how to best prepare her child to deal with those situations.

In part, most parents failed to recognize that as their children would turn into young people, adolescents and then adults they would form their own perceptions of

themselves and might struggle as a result of not being exposed to people who are similar to them or being provided with access to a language which contributes to their identity.

Though Jason made a statement reflective of this sentiment.

Jason: I do tend to wander down the road of how Ella will deal with that because that is something that will be very different for her because she is deaf. Like you take those implants off and she is deaf so whether she will decide to be deaf or hearing is something that I think she'll wrestle with.

Support

The literature explained that it was common for parents to experience difficulty in recognizing that they need emotional support when it comes to processing the diagnosis of their child's disability. Some research explained this perceived difficulty as a result of the meaning that parents constructed of their child's disability (Brett, 2004). This was very much the situation for the parents in this study. Their constructed meaning of deafness left them with little need to seek further emotional support. During the initial period immediately following the diagnosis, parents acknowledged the need for emotional support but some indicated that this was a need that was to be met by their spouse or family. These findings are contrary to other studies in which parents have identified the ways in which they wish to be emotionally supported from professionals (Sarajarvi, Haapamaki, & Paavilainen, 2006). Asking for professional emotional support has been described in the literature as sometimes being viewed as a failure or loss of parental autonomy and responsibility (Brett, 2004). Understanding that this may be a factor as to why parents do not seek emotional support may perhaps provide supporters a different way in which to approach families (Brett, 2004). In the design of EHDI programs, it was the intention that a Family Support Worker (FSW) provides emotional

support for parents. But the role of the FSW received mixed reviews from the families in this study. Parents did agree that for the most part having one touchstone person, who was knowledgeable in the field and about the services available, was helpful. A significant component of parents' perceptions of being supported had to do with having a strong partnership with their supporters and feeling that there was someone there for them whenever help was needed. For many parents this relationship did not develop with the FSW. To understand why this relationship did not develop, it is helpful to examine where it did develop.

Parents identified their need to move forward into early intervention services. Parents felt their needs were met when they connected to speech therapists or the Cochlear Implant teams. Parents wanted professionals who were treating their child's hearing loss and who were willing to provide them with what their next steps should be. Parents wanted guarantees about prognosis in terms of successful spoken language development for their children which all but two families indicated they received. The desire to pursue spoken language is common in the literature, as is parents' desire for a step by step outline of a path to follow. In a study by Fitzpatrick and colleagues (2008), parents also identified this as a need but indicated it was not met. Contrary to the parents in their study, parents in this study appeared not to be open to processing divergent information or perspectives (Steinberg & Bain, 2001) regarding communication options once they heard the information that met their needs. Their professional support interactions served to solidify their decision to pursue spoken language to the exclusion of any other, specifically signed language. In fact parents like Julia and Adam shared how much they disliked professionals who tried to prepare them for a world in which cochlear

implants did not work. There were only a couple of noteworthy exceptions. Hannah explained that she came to that decision on her own as a result of feeling unable to learn the language and therefore to teach her child two languages. In contrast Elizabeth's experience of being told she should pursue only spoken language, she hypothesized made her even more committed to pursuing both.

While it is very positive to report that parental needs were met post diagnosis within the context of an EHDI program, the more common occurrence in the literature is indicative of the opposite (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008). What is called into question, as a result of these parental perceptions of support is whether the support is truly being provided in a context of family centeredness. Dunst, Trivette, and Johanson (1994) identified essential characterizes of family centered service delivery as acceptance, a lack of judgment, full disclosure of information, bidirectional information sharing, and dependability. It also involves forging equal partnerships with self-aware professionals who understand their own strengths and biases that influence their communication patterns, values, beliefs, needs, and interpersonal skills (Rosin, et al, 1996). Experiences characterized by these traits appeared to be missing for the families in this study.

Evidence of these missing factors comes from parents' descriptions of feeling unable to demand supportive qualities like empathy and sensitive from those professionals with technical expertise. Many parents shared even being asked to sign forms indicating that they would not use signed language with their child. This is not indicative of a family centered service delivery model. Some of the experiences described by parents also seemed to indicate that parents were not making decisions at their own

pace. Claire and Eric needed to go home to Google cochlear implants because they did not feel as though it was explained to them. Hannah had to tell the surgeon that she needed time to make her decision. These examples do not reflect the path of family centered service delivery.

Parents also described experiences that had the potential to contribute to or give rise to ongoing feelings related to grief. Parents shared struggling in how to navigate avenues of intervention when they received conflicting information or when they developed communication philosophies that were divergent from professionals. Claire, Eric, Elizabeth and Zoe all shared these experiences. Parents also described experiences that reflected feeling measured and judged by professionals regarding their ability to do therapy follow through and even regarding their skills in parenting. Parents indicated that they feared addressing concerns with professionals because it may have altered the services that their children received. Operating from a place of fear does not enable parents to gain confidence as a parent or be acknowledged as the child's caregiver (Linbald, Rasmussen, & Sandman, 2005b). If parents do not have the opportunity to form supportive relationships with individual professionals outside of this type of service delivery model they may feel locked into initial decisions. There is the potential that if these parents ever came to understand different aspects of their child's disability, or if their feelings or philosophies changed over time and they ceased to identify with that one individual, they may feel as though they had nowhere to turn (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). A model of service delivery as described above does not support parents in identifying their strengths or empower them to challenge assumptions and create their own path.

Another component of support discussed in the literature was that professional support had a direct effect on helping parents to make contact with other parents. As with emotional support, connection with other parents was not something that was viewed positively by the parents in this study. In some ways the parents' ability to focus only on the positive perhaps contributed to sentiments of isolation. Parents in this study were very sensitive to the comments of other individuals. Although as Rob and Chris explained, it was only because they perceived other people to be uncomfortable and wanted to make them feel "okay" in talking with them. Parents also shared that while they wanted reassurances, they did not want to risk exposing themselves to information they knew would prove unhelpful. Many parents also referenced Internet searches rather than connecting with other parents, as the Internet guarantees anonymity. While researchers and programs are acknowledging that the Internet can be a helpful resource to parents during the course of understanding their child's disability, other studies have indicated that parents still prefer to discuss found information with professionals (Wainscott, 2010; Porter & Edirippulige, 2007)

Implications

A number of powerful implications can be drawn from the experiences of the parents in this study. Before examining some of these implications, it is especially noteworthy to acknowledge that the parents in this study were very positive. They were positive about their overall infant hearing program experiences. They were positive and loving toward their children and they were positive and grateful for the support they received. Again to clearly emphasize, it was not the intention of this study to judge how these parents experienced and processed grief or their perceptions of support. Rather it

was to consider carefully their experiences. Through sharing these experiences, some insightful conclusions can be drawn to assist professionals who interact with families in the early stages of processing the diagnosis of a child's hearing loss.

The findings in this study support the notion that professionals must first and foremost be in constant open communication with parents in order to come to understand which factors impact their adjustment to their child's hearing loss. A commonality amongst these parents' experiences was that after the initial reaction to the diagnosis, they did not view their child's hearing loss as a tragic event, these parents identified that they experienced joy as part of their adjustment process. For supporting professionals, the ability to acknowledge joy as part of the grief experience is important because it can provide parents with the strength and empowerment to carry on with the work that they do for the sake of their children. Positivity can help parents to move forward in making complicated decisions. Acknowledging joy in grief is important for professionals to avoid overwhelming parents with messages of hopelessness. Even though parents discussed grief less easily, it continued to be part of their experiences and this has some important implications. Professionals need to help provide families the space to feel and share those heavy sentiments. If professionals focus too much on minimizing a child's hearing loss by offering solutions, there is the potential that parents may not have the opportunity to fully process their emotions.

One of the first assumptions about family centered service delivery is the acknowledgment of the family as the expert, since families know their child best and want the best for them. Therefore in family centered services, families are supported as the primary decision makers for their child (Gloeckler & Proctor, 2004). These parents,

as previously stated, knew what they wanted for their child and they actively and immediately moved forward. Yet the findings of this study must challenge professionals to closely consider whether meeting those needs of families serves them well in the long run. This is similar to the very influential conclusions of Young and Tattersall (2007). Kandel and Merrick (2007) reported, “ families capacity to prepare their children for anticipated confrontations in the real world is a major determinant for success as an adult” (pg. 1800). The parents in this current study appeared fearful of the cultural aspects of Deafness; they could not conceptualize this reality for their child. Young’s study (1999) examined the impact of intervention for children with hearing loss involving cultural aspects of deafness (i.e., exposure to signed language, Deaf role models and Deaf culture) and her findings offered a possible explanation for parents’ fears. In acknowledging that a child belongs to that group, parents are made aware of the potential ways in which they may have difficulty in coming to know their child (Young, 1999). Therefore it was understandable that parents wanted to hear that what made their child different from them, could be fixed. Yet there are potential risks to a child if a parent forges this assumption. Children growing up with even the slightest perception that something about them needs fixing can potentially damage their wellbeing and self esteem, especially as children struggle in their later years to develop a sense of identity. .

Therefore, what are professionals to do when they are presented with their own paradox in service provision? The answer is not clear or simple and more research is needed from the perspective of parents longitudinally and from parents who made different choices than the ones in this study. The following can be offered as a place to begin the discussion. To assist parents more in developing an understanding of their own

strengths, professionals might help parents build a balanced perspective. A balanced perspective for parents of children with hearing loss involves helping parents to incorporate positive perceptions of deafness into their schema of what it is to be deaf. This is not a simple message for hearing parents to understand or for professionals to deliver.

Professional attempts to assist parents in balancing the positive perceptions of deafness with their initial negative perceptions must extend beyond the experiences that parents shared in this study. Parents shared how what appeared to be uplifting messages about successful Deaf individuals were only seen in the form of limitations. A Deaf astronaut was still Deaf and a Deaf professor was limited by working in a Deaf Studies Program. It was unfortunate that very few of the parents came to find any of that balance in terms of the meaning they constructed of deafness. That lack highlights the need for programs to rethink how, what and when all types of information is provided.

Recommendations have been made that professionals should wait six months after parents get a diagnosis of a child's disability before they become involved so that parents have a chance to process the medical information on their own or with trusted loved ones before they are prepared to discuss matters in a group setting, with other parents or with professionals (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). The need to give parents time in the context of hearing detection is confounded by the need to ensure children receive early access to language. Parents have embraced the message that early access and exposure to spoken language ensures optimal outcomes, yet there is a lack of this same type of needed recognition for signed language exposure. Many parents in this study were under the assumption that their children could easily learn signed language if

they decided later as an adult that they did not want the implants. What may be more helpful is to assist parents in being open to their options. Also rather than having parents feel that their decision of one moment sets the course forever, the perspectives needs to be shifted so parents come to see that they will be making a series of decisions that can change as circumstances change. It is also worth noting, as many of the parents in this study indicated, that joy was felt through interactions with their child. There is the possibility that families, even those who pursue cochlear implants, could begin to communicate with their child from birth using signed language rather than waiting, their breath baited that first year until the implant gets activated. This would require a shift in the polarization of information in the field that indicates signed language is a hindrance to the development of spoken language.

Limitations

There are a few limitations to this study worth considering. The first limitation of this study was the homogeneity of the participants on a number of levels. The first limitation involved the demographics of the participants. All parents were from large urban centers with good access to intervention services. This limited contribution the experience of those families who may have experienced more stress as a result of potentially lesser access to intervention options. All parents had university experience and on the whole were a very well-educated group. There is the potential that the level of parental education influenced their willingness to share experiences other than those indicative of complete adjustment or acceptance of their child's hearing loss. Research has shown that more educated participates are more likely to anticipate what the interviewer wants to hear and adjust their responses accordingly. All of the participants

also reported high household incomes. Mothers were able to stay home during their first year and some extended their leave from work. It is interesting to note that participant samples with high socioeconomic status (SES) was also common in other parental perspective studies within the context of EHDI programs (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Young & Tattersall, 2007). A possible explanation for the similarity in demographic characteristics is that perhaps these are the types of families who volunteer to participate in research studies. The findings of the study potentially could have been different if more parents had encountered financial burdens. While these parents shared challenges experienced with their financial situations such as with returning to work, feelings of guilt for wanting to be back at work and concerns about having others carry out therapy responsibilities, these parents appeared to have the freedom to make those decisions. If participants had come from lower SES backgrounds, experiences shared may have reflected their grief in not having a choice about returning to work or having the time to participate as fully in their child's therapy and development. There was also a great deal of similarity in the experiences of parent participants. All of the children in the study were receiving spoken language intervention and only two children were supplementing that with signed language intervention. Most of the children in the study also had age appropriate language at the time parents participated in the study. All of the parents in this study also expressed strong marital relationships. The fact that all the parents in this study also shared feeling very emotionally supported from their spouses may have potentially turned out differently had there been single parent participants or marriages that were strained through the process

of adjusting to their child's hearing loss. As previously discussed a lack of support can be a significant predictor in how individuals are able to manage difficult emotions.

Another limitation of this study was the use of the child language observation and interactions as a mean to provide context for the focus group discussions. These observations and interactions were potentially limited because it can often take children a number of visits to become comfortable communicating with an outsider in the same way that they do with someone familiar to them. This limitation was anticipated which is why the primary purpose of the observations was to provide a context for what parents shared about their child's language skills. In all cases parents' descriptions of their child's language skills matched those that the researcher observed.

Another limitation of the current study was that it represented a snapshot of the experience of grief in one moment of time. This can be viewed as a limitation because the expression of grief changes over time (Kandel & Merrick, 2007). A more comprehensive understanding of the grief process would lend itself well to a longitudinal study where grief could be assessed at multiple points in time. The focus of this study was a small sample of parents who were adjusting to the diagnosis of their children's hearing loss. The findings are potentially limited in their application to other supporting professionals working with families whose children are being diagnosed with different types of disabilities. However, while disabilities can be characterized by various factors such as severity, chronicity, and predictability, what is of greater importance is the value that parents place on that characteristic. Possessing an awareness of what factors impact the grief reaction regardless of disability types is dependent on the values and perspectives of the individuals. This following statement was made during a focus group discussion

about a conversation one mother had with a friend who had a child with a life threatening rare genetic disorder,

I thought it would be much harder for my friend but she seems to think it's worse with my son, just because everything is constantly breaking down on him - the battery, the coils, everything - and we tend to have more appointments. Her problems tend to me more life threatening when she has a problem but ours are daily.

In order to recruit enough participants, inclusion criteria specified parameters around severity of hearing loss and parameters of time subsequent to the diagnosis. These parameters had to be larger than what might otherwise have been desired. Therefore it is possible that some of the conclusions are applicable to the cochlear implant group specifically. In most cases the conclusions and implications were applicable to all participants. The findings of this study also cannot be generated across cultures as only one cultural group was represented in this study.

Conclusion

The findings in this study regarding parental grief reaction are different from studies in the past that have described the grief process as parents overcoming a tragic experience. Other studies have also attributed some of the negative response of parents to their child's diagnosis to the professionals working with the parents. The parents in this study did express grieving immediately following their child's diagnosis, yet these clearly articulated these feelings were short lived. The meaning of deafness that many of the parents constructed fit the medical model. They saw their child's hearing loss as something that had the potential to be fixed.

Many other parents turn to external support to help process their grief to alleviate their sense of loss and help them make meaning of their child's disability, however, many

of the parents in this study certainly did not see the value of that type of experience. Yet despite their resistance to acknowledge certain feelings or realities, all of these parents were able to mobilize and focus their energies on doing what they felt needed to be done. This indicated a healthy part of grief processing. Parents also had a positive sense of making an impact on the world around them as a result of their experiences. Therefore for the parents in this study, their grief was very complex and was not similar to other stage based grief theories or those similar to chronic sorrow.

It would be interesting for further research to follow parents longitudinally to access changes in feelings over a longer time span as well to examine where families turn to for support. Greater research into longitudinal outcomes in terms of language development in the context of EHDI programs might also provide greater insight for professionals who are working as supporters or interventionists with parents. It would also be interesting to talk with more families who have chosen to include signed language as part of their complement of services for their child, to find out how these families have arrived at their decisions, what meaning of deafness they have constructed and whether their grief process is any different from those outlined above.

References

- Attig, T. (1991). The importance of conceiving grief as an active process. *Death Studies*, 15, 385-393.
- Anagnostou, F., Graham, J., & Crocker, S. (2007). A preliminary study looking at parental emotions following cochlear implantation. *Cochlear Implants International*, 8, 68-86.
- Barnett, D., Clements, M., Kaplan-Estrin, M., Fialka, J. (2003). Building new dreams. Supporting parents' adaptation to their child with special need. *Infants and Young Children*, 16, 184-200.
- Benedict, B., & Raimondo, B. (2003). Family rights, legislation, and policies: What professionals need to know to promote family involvement and advocacy. In B. Bodner-Johnson & M. Sass-Leher (Eds.), *The young deaf or hard of hearing child: A family centered approach to early education* (pp. 61-95). Washington, DC: Paul Brookes.
- Bogdan, R., & Biklen, S. (2007). *Qualitative Research for Education: An Introduction to Theories and Methods* (5th Ed). Boston: Allyn and Bacon.
- Bohannon, J. R. (1990-1991). Grief responses of spouses following the death of a child: A longitudinal study. *Omega*, 22, 109-121.
- Boss, P. (2002). *Family Stress Management: A Contextual Approach* (2nd ed.). London, U.K.: Sage Publications Inc.
- Bowlby, J. (1980). *Attachment and Loss: Vol 3. Sadness and Loss*. New York: Basic Books.
- Boyd, J. (2001). A process for delivering bad news: Supporting families when a child is

- diagnosed. *The Journal of Neuroscience Nursing*, 33, 14-20
- Brett, J. (2004). The journey to accepting support: how parents of profoundly disabled children experience support in their lives. *Paediatric Nursing*, 16, 14-18.
- Brown, M., Bakar, Z., Richards, F., & Griffin, P. (2006). Family functioning, early intervention support, and spoken language and placement outcomes for children with profound hearing loss. *Deafness and Education International*, 8, 207-226.
- Brown, C., & MacKenzie, S. (2005). The Role of the Audiologist and Family Support Worker on the Ontario Infant Hearing Program: A Team Approach. *Journal of Speech-Language Pathology and Audiology*, 29(3), 106-110.
- Bruce, E., & Schultz, C. (2001). *Nonfinite Loss and Grief*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Canadian Working Group on Childhood Hearing. (2005). *Early hearing and communication development: Canadian Working Group on Childhood Hearing (CWGCH) resource document*. Ottawa, Ontario: Minister of Public Works and Government Services Canada.
- Calderon, R., & Greenberg, M. (1999). Stress and coping in hearing mothers of children with hearing loss: Factors affecting mother and child adjustment. *American Annals of the Deaf*, 144, 7-18.
- Calderon, R., & Naidu, S. (2000). Further support for the benefits of early identification and intervention for children with hearing loss. *Volta Review*, 100, 53-84.
- Carpenter, B. (Ed). (1997). *Families in context: Emerging trends in family support*. Fulton: David Publishers.
- Clark, T., Earls, M., & McCollum, J. (2004). Diagnostic Assessment Training e-

- Resource. CENTe-R, UNCG. Retrieved September 15, from <http://center.uncg.edu/training/modules/>
- Clemens, C., & Davis, S. (2001). Minimizing false-positives in universal newborn hearing screening: A simple solution. *Pediatrics*, *107*(3), 1-3.
- Clements D.B., Copeland L.G. & Loftus M. (1990) Critical times for families with a chronically-ill child. *Pediatric Nursing* *16*, 157-161.
- Corcoran, J.A., & Stewart, M. (1998). Stories of stuttering: A qualitative analysis of interview narratives. *Journal of Fluency Disorders*, *23*, 247-264.
- Corcoran, J. A., Stewart, M., Glynn, M., & Woodman, D. (2000). Stories of parents and children with hearing loss: A qualitative analysis of interview narratives. In R. C. Seewald (Ed.), *A sound foundation through early amplification: Proceedings of an international conference* (pp. 167-174). Stäfa, Switzerland: Phonak AG.
- Creswell. J. (2005). *Education research: Planning, conducting and evaluating quantitative and qualitative research*. New Jersey: Pearson Education Inc.
- Cummings, E. M., Davis, P.T., & Campbell, S.B. (2000). *Developmental psychopathology and family process: Theory, research, and clinical implications*. New York: Guilford.
- Davis, R. (2004). New understanding of parental grief: Literature review. *Journal of Advanced Nursing*, *46*, 506-513.
- DesGeorges. J. (2003). Family perceptions of early hearing, detection, and intervention systems: listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews*, *9*, 89-93.
- Donalek, J., 2004. Phenomenology as a qualitative research method. *Urologic Nursing* *23*

(5), 349–354.

- Drew, N. (2001). Meaningfulness as an epistemologic concept for explicating the researcher's constitutive part in phenomenologic research. *Advances in Nursing Science, 23*, 16-31.
- Dunst, Trivette, & Johanson (1994). *Supporting and strengthening families: Methods, strategies, and practices*. Cambridge, Mass: Brookline Books.
- Durieux-Smith, A., Seewald, R., & Hyde, M. (2000). CASLPA - CAA Position on universal newborn and infant hearing screening in Canada. *Journal of Speech-Language Pathology and Audiology, 24*(3), 139-141.
- English, K. (2007, Fall). Informing parents of their child's hearing loss. Paper presented at the Oticon Canada Pediatrics Seminar, Kananaskis, Alberta.
- Featherstone, H. (1980). *A difference in the family: Living with a disabled child*. New York, Basic Books, Inc.
- Feher-Prout, T. (1996). Stress and coping in families with deaf children. *Journal of Deaf Studies and Deaf Education, 1*, 155-166.
- Ferguson, P. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *The Journal of Special Education, 36*, 124-130.
- Friehe, A., Bloedow, A., & Hesse, S. (2003). Counseling families of children with communication disorders. *Communication Disorder Quarterly, 24*, 221-220.
- Finitzo, T., & Crumley, W. (2000). A model universal newborn hearing screening program for hospitals and birthing facilities. *Journal of Speech and Language Pathology and Audiology, 24*, 130-138.

- Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I., & Coyle, D. (2008). Parents' needs following identification of childhood hearing loss. *American Journal of Audiology, 17*, 38-49.
- Fitzpatrick, E., Graham, I., Durieux-Smith, A., Angus, D., & Coyle, D. (2007). Parents' perspectives on the impact of the early diagnosis of hearing loss. *International Journal of Audiology, 46*, 97-106.
- Foley, G.M. (2006). The grief loss cycle. In G.M. Foley & J.D. Hochman (Eds.), *Mental health in early intervention: Achieving unity in principles and practice* (pp.) Baltimore: Paul Brookes Publishing.
- Fortier, L., & Wanlass, R. (1984). Family crisis following the diagnosis of a handicapped child. *Family Relations, 33*, 13-24.
- Gallagher, P., Easterbrooks, S., & Malone, D. (2006). Universal newborn hearing screening and intervention: Assessing the current collaborative environment in service provision. *Infants and Young Children, 19*, 59-72.
- George, A., Vickers, M., Wilkes, L., & Barton, B. (2006). Chronic grief: Experiences of working parents of children with chronic illness. *Contemporary Nurse, 23*, 228-242.
- Gilbert, K. (2001). We've had the same loss, why don't we have the same grief: Loss and differential grief in families. *Death Studies, 20*, 269-283.
- Gilbert, K. (2007). *Grief in a Family Context*. Retrieved May 05, 2008, from Indiana University, <https://www.indiana.edu/~familygrf.html>.
- Giorgi, A. (1989). One type of analysis of descriptive data: Procedures involved in following a phenomenological psychological method. *Methods, 1*, 39-61.

- Gloeckler, P. & Proctor, R. (2004). Family Support. Training e-Resource. CENTe-R, UNCG. Retrieved September 15, 2006, from <http://center.uncg.edu/training/modules/>
- Godress, J., Ozgul, S., Owen, C., & Foley-Evan, L. (2004). Grief experiences of parents whose children suffer from mental illness. *Austrian and New Zealand Journal of Psychiatry*, 39, 88-94.
- Graungaard, A.H., & Skov, L. (2006). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and need, when the newborn child is severely disabled. *Child: Care, Health and Development*, 33, 296–307.
- Greco, V., Sloper, P., Webb, R., & Beecham, J. (2006). Key worker services for disabled children. *Health and Social Care in the Community*, 14, 445-452.
- Groenewald, T. (2004) A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3. Retrieved from http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/groenewald.pdf
- Hall, S. (1996). An exploration of parental perception of the nature and level of support needed to care for their child with special needs. *Journal of Advanced Nursing*, 24, 512-521.
- Hammersley, M. (2000). *Taking sides in social research*. London: Routledge.
- Hansson R.O., Carpenter B.N., Fairchild S.K. (1993). Measurement issues in bereavement. In: Stroebe M, Stroebe W, Hansson R.O. (eds). *Handbook of Bereavement: Theory, Research, and Intervention*. New York, NY: Cambridge University Press, 62-74.
- Hasnat, M., & Graves, P. (2000). Disclosure of developmental disability: A study of

- paediatricians' practices. *Journal of Pediatrics and Child Health*, 36, 27–31.
- Heiman, T. (2002). Parents of children with disability: Resiliency, coping and future expectations. *Journal of Developmental and Physical Disabilities*, 14, 160-171.
- Hergils, L. & Hergils, A. (2000). Universal neonatal hearing screening- parental attitudes and concern. *British Journal of Audiology*, 34, 321-327.
- Hill, R. (1958). Generic features of families under stress. *Social Casework*, 49, 139-150.
- Hilton, D. (1993). *Counseling parents of children with chronic illness or disability*. Baltimore: Paul H. Brookes Publishing Co.
- Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *Journal of Deaf Studies and Deaf Education*, 11, 493-513.
- Holland, S. (1996). The special needs of parents. *Education Psychology in Practice*, 12, 24-30.
- Horowitz, M. J., Wilner, N., Marmar, C., & Krupnick, J. (1980). Pathological grief and the activation of latent self images. *American Journal of Psychiatry*, 137, 11577 - 1160.
- Howe, D. (2006). Disabled children, parent-child interaction and attachment. *Child and Family Social Work*, 11, 95-106.
- Hycner, R H (1985) "Some guidelines for the phenomenological analysis of interview data," *Human Studies* 8, 279-303
- Hyde, M. (2005). Newborn hearing screening programs: Overview. *The Journal of Otolaryngology*, Volume 34, Supplement 2, S70-S78.
- Kandel, I., & Merrick, J. (2003). The birth of a child with disability: Coping by parents

- and siblings. *The Scientific World Journal*, 3, 741-750.
- Kandel, I., & Merrick, J. (2007). The child with a disability: Parental acceptance, management and coping. *Child Health and Human Development*, 7, 1799-1809.
- Kearney, P., & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34, 582-592.
- King, G. & Meyer, K. (2006) Service integration and co-ordination: a framework of approaches for the delivery of co-ordinated care to children with disabilities and their families. *Child: Care, Health & Development*, 32, 477-492.
- Kelly, S., & Bibby, M.A., (2008). Parents' Experience in a Locally Initiated Newborn Hearing Screening Program. *Canadian Journal of Speech – Language Pathology and Audiology*, 32, 92-100.
- Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: The case for reflexivity. *Journal of Advanced Nursing*, 28, 882-890.
- Krueger, R. & Casey, M. (2000). *Focus Groups; a Practical Guide for Applied Research*. California, Sage: Thousand Oak.
- Kubler Ross, E. (1969). *On death and dying*. New York: Macmillan.
- Kurtzer-White, E., & Luterman, D. (2003). Families and children with hearing loss: Grief and coping. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(4), 232-235.
- Kvale, S. (1996). *Interviews: An introduction into qualitative research interviewing*. Thousand Oaks: Sage.
- Land, G.H. (1998). Reconstructing motherhood in the age of “perfect babies: Mothers of

- infants and toddlers with disabilities. *Journal of Women in Culture and Society*, 24(1), 69-99.
- Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science Medicine*, 47, 865-875.
- Lederberg, A., & Golbach, T. (2001). Parenting stress and social support in hearing mothers of deaf and hearing children: A longitudinal study. *Journal of Deaf Studies and Deaf Education*, 7, 330-345.
- Lester, S. (1999). An introduction to phenomenological research. Retrieved from <http://www.sld.demon.co.uk/resmethy.pdf>
- Lewis, V. (2003). *Developmental Disability*. Oxford: Blackwell.
- Linblad, B.M., Rasmussen, B.H., & Sandman, P.O. (2005). Being in tune with oneself, children, and parents: Meaning of being a supporter to families with children who have disabilities as narrated by parent-selected professionals. *International Journal of Pediatric Nursing*, 20, 214-223.
- Linblad, B.M., Rasmussen, B.H., & Sandman, P.O. (2005b). Being invigorated in parenthood: Parents; experiences of being supported by professionals when having a disabled child. *International Journal of Pediatric Nursing*, 20, 288-297.
- Luterman, D. (2001). *Counseling Persons With Communication Disorders and Their Families*, (4th ed.). Austin, TX: Pro-Ed
- Luterman, D. (2006). The counseling relationship, *The ASHA Leader*, 11, 8-10.
- Luterman, D., & Kutzer-White, E. (1999). Identifying hearing loss: Parents' needs. *American Journal of Audiology*, 8, 13-18.
- Lynch, R., & Morley, K. (1995). Adaptation to pediatric physical disability within the

- family system: A conceptual model for counseling families. *The Family Journal: Counseling and Therapy for Couples and Families*, 3, 207-217.
- MacGregor, P. (1994). Grief: The unrecognized parental response to mental illness in a child. *Social Work*, 39, 160-166.
- Mapp, I., & Hudson, R. (1997). Stress and coping among African American and Hispanic parents of deaf children. *American Annals of the Deaf*, 142, 48-56.
- Marlow-Iroff, M., & Johnson, H. (2005). Health and parenting issues in childhood and adolescence. In S.J. Farenga, B.A. Joyce, D. Ness (Eds.), *The encyclopedia on educating and human development* (pp. 867-902). New York: M.E. Sharp.
- Martin, K., & Elder, S. (1993). Pathways through grief: A model of the process. In J.D. Morgan (Ed.). *Personal care in an impersonal world: A multidimensional look at bereavement*. New York: Baywood Publishing.
- Marshark, L.E., & Prezant, F. (2007). *Married with special needs children: A couples guide to staying connected*. Bethesda, MD: Woodbine House
- Marvin, R., & Pianta, R. (1996). Mothers' reaction to their child's diagnosis: Relations with security of attachment. *Journal of Clinical Child Psychology*, 25, 436-445.
- Mary, L.N. (1990). Reactions of black, Hispanic, and white mothers to having a child with handicaps. *Mental Retardation*, 28, 1-5.
- McCubbin, H., & Patterson, J. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage and Family Review*, 6, 7-37.
- McKinnon, C., Moran, G., & Pederson, D. (2004). Attachment representations of Deaf adults. *Journal of Deaf Studies and Deaf Education*, 9, 366-386.
- McMillan, J. (2008). *Educational research: Fundamentals for the consumer- 5th edition*

United States: Pearson Education Inc.

- Meinzen—Derr, J., Lim, L., Choo, D., Buyniski, S., & Wiley, S. (2008). Pediatric hearing impairment caregiver experience: *impact of the duration of hearing loss on parental Stress*. *International Journal of Pediatric Otolaryngology*, 72, 1693-1703.
- Middleton, W., Raphael, B., Martinek, N., & Misso, V. (1993). Pathological grief reactions. In M. S. Stroebe, W. Stroebe, & R.O.Hansson (Eds.), *Handbook of bereavement: Theory, research and intervention* (pp. 447-61). New York: Cambridge Press.
- Miles, M.B. & Huberman, A.M. (1984). *Qualitative data analysis, a sourcebook for new methods*. Newbury Park; Sage.
- Mindel, E., & Vernon, M. (1974). *They grow in silence: The deaf child and his family*. Silver Spring, MD: National Association of the Deaf.
- Mitchell, W., & Sloper, P. (2001). Information that informs rather than alienated families with disabled children: developing a model of good practice. *Health and Social Care in the Community*, 10, 74-81.
- Neimeyer, R. A. (2001). Meaning Reconstruction and Loss. In Neimeyer, R. A. *Meaning Reconstruction and the Experience of Loss*. Washington: American Psychological Association.
- Northern, J., & Downs, M.P. (1991). *Hearing in children* (4th Ed). Baltimore, MD: William & Wilkins.
- Olshansky, S. (1962). Chronic Sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190-194.
- Orme, D. (2005). A qualitative examination of mothers' resolution or non-resolution of

- their childrens' disability of down syndrome or autism using a cognitive intervention. *The Qualitative Report*, 10, 561-592.
- Pain, H. (1999). Coping with a child with disability from the parents' perspective: The function of information. *Child: Care, Health, & Development*, 25, 299-312.
- Park, A., Warner, J., Sturgill, N., & Alder, S. (2006). A survey of parental views regarding their child's hearing loss: A pilot study. *Otolaryngology- Head and Neck Surgery*, 134, 794-800.
- Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oakes, CA: Sage Publications, Inc.
- Pelchat, D., & Ricard, N., Bouchard, J.M., & Perreault, M., Saucier, J.F., Berthiaume, M., & Bisson, J. (1999). Adaptation of parents in relation to their 6-month-old infant's disability type. *Child: Care, Health and Development*, 25, 377-397.
- Pianta, R., Marvin, R., Britner, P., & Borowitz, K. (1996). Mothers' resolution of their children's diagnosis: organized patterns of caregiving representations. *Infants Mental Health Journal*, 17, 239-256.
- Pianta, R., Marvin, R., & Morog, M. (1999). Resolving the past and present: relations with attachment organization. In J. Solomon & C. George (Eds.), *Attachment Disorganization* (pp. 379-398). New York, NY: Guilford Press.
- Pipp-Siegel, S., Sedey, A., & Yoshinaga-Itano, C. (2002). Predictors of parental stress in mothers of young children with hearing loss. *Journal of Deaf Studies and Deaf Education*, 7, 1-17.

- Poon, B. (1999). *Parental reaction to deafness in children: A grounded theory investigation*. Unpublished master's thesis, University of Alberta, Edmonton, Alberta, Canada.
- Poon, B. (2005). Construction of re-screen results in a universal newborn hearing screening program: The discourse of parents and screeners (Doctoral dissertation, University of British Columbia, 2005). Dissertation Abstracts International,
- Porter, A., & Edirippulige, S. (2007). Parents of deaf children seeking hearing-loss related information on the Internet: the Australian experience. *Journal of Deaf Studies and Deaf Education, 12*, 518-529.
- Poulakis, Z., Barker, M., & Wake, M. (2003). Six month impact of false positives in an Australian infant hearing screening program. *Archives of Disease in Childhood, 88*, 20-24.
- Powers, L.E. (1993). Disability and Grief: from tragedy to challenge. In G.Singer and L.Powers (Eds.), *Families, Disability, and Empowerment: Active coping skilld and strategies for family intervention* (pp119-155). Baltimore: Paul Brookes Publishing CO.
- Proctor, R. (2004). Early Intervention Teaming. Training e-Resource. CENTe-R, UNCG. Retrieved September 15, from <http://center.uncg.edu/training/modules/>
- Proctor, R., & Gloeckler, P. (2004). Service Delivery Training e-Resource. CENTe-R, UNCG. Retrieved September 15, from <http://center.uncg.edu/training/modules/>
- Quittner, A., Glueckauf, R., & Jackson, D. (1990). Chronic parenting stress: Moderating versus mediating effects of social support. *Journal of Personality and Social Psychology, 59*, 1266-1278.

- Rahi, J. S., Manaras, I., Tuomainen, H., & Hundt, G. L. (2004). Meeting the needs of parents around the time of diagnosis of disability among their children: Evaluating a novel program for information, support, and liaison by key workers. *Pediatrics, 114*, 477-482
- Robinshaw, H., & Evans, R. (2003). Service provision for preschool children who are deaf: Parents' perspective. *Journal of Social Work in Disability and Rehabilitation, 2*, 3-39.
- Roos, S. (2009). Chronic Sorrow. In C.D. Bryand & D.L. Peck (Eds.), *Encyclopedia of death and the human experience*. Thousand OAsk. CA: Sage Publications.
- Rosin, P., Whitehead, A., Tuchman, L., Jesien, G., Begun A., & Irwin, L. (1996). Partnerships in Family-Centered Care: A guide to collaborative early intervention.
- Roush, J. (2000). Implementing Parent-Infant Services: Advice from Families. In R.C. Seewald (Ed.), *A sound foundation through early amplification: Proceedings of an international conference*, (pp. 159-166). Switzerland; Phonak, AG.
- Roush, J., & Harrison, M. (2002). What parents want to know at diagnosis and during the first year. *Hearing Journal, 55*, 52-54.
- Rush, D., Sheldon, M., & Hanft, B. (2003). Coaching families and colleagues: A process for collaboration in natural settings. *Infants and Young Children, 16*, 33-47.
- Russ, S. A., Kuo, A. A., Poulakis, Z., Barker, M., Rickards, F., Saunders, K., et al. (2004). Qualitative analysis of parents' experience with early detection of hearing loss. *Archives of Disease in Childhood, 89*, 353-358.
- Sanders, M. (1992). *Surviving grief and learning to live again*. New York: John Wiley and Sons, Inc.

- Sarajarvi, A., Haapmaki, M.L., & Paavilainen, E. (2006). Emotional and informational support for families during their child's illness. *International Nursing Review*, 53, 205-210.
- Scorgie, K., Wilgosh, L., & McDonald, L. (1998). Stress and coping in families of children with disabilities: An examination of recent literature. *Developmental Disabilitation Bulletin*, 26(1), 22-42.
- Seligman, M., & Darling, B. (2007). *Ordinary families, special children: A systems approach to childhood disability* (3rd ed.). New York: The Guilford Press.
- Sen, E., & Yurtsever, S. (2007). Difficulties experienced by families with disabled children. *Journal for Spectacular in Pediatric Nursing*, 12, 238-252.
- Schneider, J. (1984). *Stress, Loss, & Grief*. Baltimore: University Parks Press.
- Sheeran, T., Marvin, R., & Pianta, R. (1997). Mothers' resolution of their child's diagnosis and self reported measures of parenting stress, marital relations, and social support. *Journal of Pediatric Psychology*, 22, 197-212.
- Sloman, L., Springer, S., & Vachon, M. (1993). Disordered communication and grieving in deaf member families. *Family Processes*, 32, 171-183.
- Sloper, P. (1999). Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health and Development*, 25, 85-99.
- Sloper, P., & Turner, S., (1993). Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine and Child Neurology*, 35, 167-188.
- Solnit, A.J., & Stark, M.H. (1961). Mourning and the birth of a defective child. *Psycho-Analytic Study of the Child*, 16, 523-537.

- Sorrell, J.M. & Redmond, G.M. (1995). Interviews in qualitative nursing research: differing approaches for ethnographic and phenomenological studies. *Journal of Advanced Nursing*, 21, 1117-1122.
- Steinberg, A., & Bain, L. (2001). Parental decision making for infants with hearing impairment. *International Pediatrics*, 16, 1-6.
- Stewart, D., Shamdasani, P., & Rook, D. (2007). *Focus Groups: Theory and Practice (2nd Ed)*. London: Sage Publications.
- Stredler-Brown, A. (2004). Family centered intervention: Proven strategies to assure positive outcomes. In R. C. Seewald (Ed.), *A sound foundation through early amplification: Proceedings of an international conference* (pp. 185-195). Chicago: Phonak AG.
- Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: rationale and description. *Death Studies*, 23, 197-224
- Stroebe M, Stroebe W, & Hansson R.O. (Eds.). (1993). *Handbook of Bereavement: Theory, Research, and Intervention*. New York: Cambridge University Press, 62-74.
- Taanila, A., Jarvelin, M.R., & Kokkonen, J. (1996). The long-term effects of children's early onset disability on marital relationships. *Developmental Medicine & Child Neurology*, 38(7), 567-577.
- Taanila, A., Jarvelin, M.R., & Kokkonen, J. (1998). Parental guidance and counseling by doctors and nursing staff: parents' views of initial information and advice for families with disabled children. *Journal of Clinical Nursing*, 7, 505-511.

- Tattersall, H., & Young, A. (2006). Deaf children identified through newborn hearing screening: Parents' experiences of the diagnostic process. *Child Care Health Development, 32*, 33-45.
- Taylor, S.E., & Brown, J.D. (1998). Illusions and well-being: a social psychological perspective on mental health. *Psychological Bulletin, 103*, 193-210.
- Trute, B., Hiebert-Murphy, D., & Levine, K. (2007). Parent appraisal of the family impact of childhood developmental disability: Times of sadness and times of joy. *Journal of Intellectual & Developmental Disability, 32*, 1-9.
- Vaccari, C. & Marschark, M. (1997). Communication between parents and deaf children: Implications for socio-emotional development. *Journal of Child Psychology, 38*, 793-801.
- Vohr, B.R., Letourneau, K.S., & McDermott, C. (2001). Maternal worry about neonatal hearing screening. *Journal of Perinatology, 21*, 15-20.
- Wainscott, S. (2010). Decision making in families engages in early hearing detection programs: A qualitative study. Unpublished doctoral dissertation from Gallaudet University. Retrieved from http://gateway.proquest.com/openurl%3furl_ver=Z39.88-2004%26res_dat=xri:pqdiss%26rft_val_fmt=info:ofi/fmt:kev:mtx:dissertation%26rft_dat=xri:pqdiss:3441367
- Weichbold, V., & Welzl-Mueller, K. (2001). Maternal concern about positive test results in universal newborn hearing screening. *Pediatrics, 108*(5), 1111- 1116.
- Weichbold, V., Welzl-Mueller, K., & Mussbacher, E. (2001). The impact of information on maternal attitudes towards universal neonatal hearing screening. *British Journal of Audiology, 35*, 59-99.
- Wertz, F. (2005). Phenomenological research methods in counseling psychology. *Journal*

of Counseling Psychology, 52, 167-177.

Willgerodt, M.A. (2003). Using focus groups to develop culturally relevant instruments.

Western Journal of Nursing Research, 25, 798-814.

Wood Jackson, C., & Turnbull, A. (2004). Impact of deafness on family life: A review of the literature. *Topics in Early Childhood Special Education*, 24, 15-29.

Woolfson, L. (2004). Family well-being and disabled children: A psychosocial model of disability-related child behaviour problems. *British Journal of Health Psychology*, 9, 1-13.

Worden, W. (2002) *Grief Counseling and Grief Therapy*, (3rd ed.). New York: Springer.

Yoshinaga-Itano, C., & Apuzzo, M. (1998). Identification of hearing loss after age 18 months is not early enough. *American Annals of the Deaf*, 143, 380-387.

Young, A. (1999). Hearing parents' adjustment to a deaf child- the impact of a cultural-linguistic model of deafness. *Journal of Social Work Practices*, 13, 157-176

Young, A., Jones, D., Starmer, C., & Sutherlaand, H. (2005). Issues and dilemmas in the production of standard information for parents of young deaf children – Parents' views. *Deafness and Education International*, 7, 63-76.

Young, A., & Tattersall, H. (2005). Parents' of deaf children evaluative accounts of the process and practice of universal newborn hearing screening. *Journal of Deaf Studies and Deaf Education*, 10, 134-45.

Young, A., & Tattersall, H. (2007). Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education*, 12(2), 209-220.

- Young, A., Carr, G., Hunt, R., McCracken, W., Skipp, A., & Tattersall, H. (2006). Informed choice and deaf children: Underpinning concepts and enduring challenges. *Journal of Deaf Studies and Deaf Education, 11*, 322-336.
- Yoshinaga-Itano (2000). Counseling Strategies. Paper presented at the Manitoba Roundtable for Early Hearing Detection and Intervention, Winnipeg, Manitoba.
- Yoshinaga-Itano, C. (2003). From screening to early identification and intervention: discovering predictors to successful outcomes for children with significant hearing loss. *Journal of Deaf Studies and Deaf Education, 8*, 11-30.
- Yoshinaga-Itano. (2003). Early intervention after universal newborn hearing screening: Impact on outcomes. *Mental Retardation and Developmental Disabilities, 9*, 252- 266.
- Yoshinaga-Itano, C. (2001), The social-emotional ramifications of universal newborn hearing screening, early identification and intervention of children who are deaf or hard of hearing. In R. C. Seewald (Ed.), *A sound foundation through early amplification: Proceedings of the second international conference* (pp. 159-166). Chicago, Illinois: Phonak AG.
- Zimmerman, I., Steiner, V., & Evatt Pond, R. (2002). *Preschool Language Scale (4th Ed)*. San Antonio, TX: The Psychological Corporation.

Appendix A
INFORMATION LETTER TO PROGRAM MANAGERS

Project Title: Parents' Grief Experience and Perception of Support in the context of an
Early Hearing Detection and Intervention Program

Researcher: Sarah Kelly, PhD Candidate, University of Manitoba

Dear Program Managers,

I am a doctoral student in Educational Psychology at the University of Manitoba. As part of my studies, I am conducting a research on parents' grief process in relation to the diagnosis of their child's hearing loss and their perceptions of the professional support received. The information gathered will provide insights into the current system, how professionals are able to support parents and what steps can be taken to implement factors that will further benefit parents.

I am writing you to request your assistance in the selecting of parent participants for my study. The proposed design of my study involves 7-10 sets of parents. The inclusion criteria is that 1) parents are 6 months to 2 1/2 years post their child's diagnosis of hearing loss through your early hearing detection and intervention program, 2) parents are hearing parents, 3) infant's hearing loss is moderate to profound, 4) there are no disabilities in addition to hearing loss and 5) both mother and father must be willing to participate. My study will involve 1) a focus group among fathers and a group discussion among mothers who have gone through the same experience of having their child diagnosed with a hearing loss and 2) a brief language observation of the infant. I will be videotaping both the language observation and the group discussion to assist me with the analysis and to enable me to consult with my university advisor, Dr. Charlotte Enns. At the conclusion of the study, all videotapes will be erased. The language

assessment should last approximately 30 minutes and will be done in the location that is most convenient for the family. The group discussion should last no more than 2 hours and the location would hopefully be central. Any suggestions that you might have about the location of the focus group would also be appreciated.

While I do intend to publish my study, please be assured that information will remain confidential. In order to help ensure confidentiality names, and the names of the specific programs will be altered or not mentioned.

If you are able to assist me with this study, you would be asked to sent out a letter and consent form to parents that meet the inclusion criteria. I will provide you with those letters and the needed mailing supplies.

I would greatly appreciate your support and assistance for this project. Please feel free to contact me or my advisor, Dr. Charlotte Enns with any questions or clarifications pertaining to the study. Our contact information is as follows:

Sarah Kelly

Dr. Charlotte Enns

Phone #

Phone #

Email

Email

Sincerely,

Sarah Kelly

Appendix B
INFORMATION LETTER TO PARENT PARTICIPANTS

Project Title: Parents' Grief Experience and Perception of Support in the context of an
Early Hearing Detection and Intervention Program

Researcher: Sarah Kelly, PhD Candidate, University of Manitoba

Dear Parents,

I am a doctoral student in Educational Psychology at the University of Manitoba. As part of my studies, I am conducting a research on parents' grief process in relation to the diagnosis of their child's hearing loss and their perceptions of the professional support received. The information gathered will provide insights into the current system, how professionals are able to support parents and what steps can be taken to implement factors that will further benefit parents.

I am writing you to ask if you would consider being a participant in this study. If you agree, my study will involve 1) a brief language observation of your child, and 2) a group discussion among fathers and a group discussion among mothers who have gone through the same experience of having their child diagnosed with a hearing loss. I will be videotaping both the language observation and the group discussion to assist me with the analysis and to enable me to share the information with my university advisor, Dr. Charlotte Enns. At the conclusion of the study, all videotapes will be erased. The language assessment should last approximately 30 minutes and will be done in the location that is most convenient for you. The group discussion should last no more than 2 hours.

If during the analysis I am unsure of the meaning or interpretation of any comment, I will clarify this with you. You will also have full access to the results of the

study if you so desire them. While I do intend to publish my study, please be assured that your information will remain confidential. In order to help ensure confidentiality your names, and the names of the specific programs you are involved with, will be altered or not mentioned. Your participation in the study is voluntary and you may withdraw at any time.

I have attached a copy of the consent form that further explains the study and your rights if you so chose to participate. If you choose to participate in this study, you can do one of the following: 1) fill out the consent form and mail it to me with the pre-paid postage envelope in your package or 2) contact me directly by telephone to express your interest and I will collect the consent form prior to our interview. Please feel free to contact me or my advisor, Dr. Charlotte Enns with any questions or clarifications that you would require before deciding on whether or not you would like to participate. Our contact information is as follows:

Sarah Kelly

Dr. Charlotte Enns

Phone #

Phone #

Email

Email

Sincerely,

Sarah Kelly

Appendix C

CONSENT FORM FOR PARENTS

Project Title: Parents' Grief Experience and Perception of Support in the context of
an Early Hearing Detection and Intervention Program

Researcher: Sarah Kelly, PhD Candidate, University of Manitoba

This consent form, a copy of which will be left with you for your records and reference is only a part of the consent process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more details about something mentioned here, or information not included here you should feel free to ask. Please take the time to read this carefully and to understand accompanying information. .

The purpose of this study is to describe parents' grief process in relation to the diagnosis of your child's hearing loss and your perceptions of the professional support you received. The information gathered will provide insights into the current system, how professionals are able to support parents and what steps can be taken or what steps have been taken to implement factors that will further benefit parents.

The procedures that are involved in the participation of this study include 1) mothers and fathers participating separately in a group discussion with other mothers and fathers respectively, and 2) a brief language observation of your child. The discussions in the groups will focus on your emotional journey from the point of diagnosis, your perception of the emotional and information support and your decision making process.

Your confidentiality will be maintained through a variety of ways: 1) videotapes will be catalogued according to numbers as opposed to participants names, 2) personal information will be altered such as persons names, and 3) only my advisor and myself will hear the original videorecordings. The videorecordings will also be destroyed after the study is completed.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Researcher:

Sarah Kelly

Phone #

Email

Supervisor:

Dr. Charlotte Enns

Phone #

Email

This study has been approved by the Education Coursework Research Committee. If you have any concerns or complaints about this project you may contact the above named persons or the Human Ethics Secretariat at 474-7122, or e-mail

margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference

(Participant's Signature)

(Date)

(Researcher's Signature)

(Date)

Mailing address if you wish to receive a summary of the results:

Appendix D

Focus Group Guide

Topics	Sample Questions
Grief - anger, loneliness, self doubt	1) Describe your experiences in first learning about your child's hearing loss? 2) What were your emotional experiences related to your child's diagnosis of hearing loss? 3) Have there been any changes in thoughts and feelings over time? Can you describe them? 4) Parents sometimes wonder or have ideas about why they have a child with special needs. Do you have anything like that that you wonder about?
Emotional & Informational Support	1) Describe your experiences in being emotionally supported by a professional? 2) Did you feel as though professionals adequately understood your priorities, needs and problems? 3) Do you recall any interactions that, perhaps retrospectively, you can say were well intended but at the time contributed to your feelings of grief? 4) What did you find was most helpful to your processing of your feelings? 5) Describe your process of information acquisition? 6) How would you define your relationship with your support worker?
Decision Making	1) Tell me about your child and how your child is developing. 2) How do you feel now about the decision that you made and the knowledge you had in order to make that decision? 3) What emotions surrounded your decision making process? Did you feel pressured or rushed?
Difference between Spouses	1) Describe whether or not your spouse was able to be a support to you? 2) In what ways was your spouse there and not there for you? 2) Describe any of the changes to your marital relationship since the birth of your child. 2) How has your perception of your parenting abilities changed over time – when you first learnt of your child's hearing loss to now.

Appendix E

GROUP DISCUSSION QUESTIONNAIRE

1. How do you feel about having participated in this focus group?

2. Did you feel as though you were provided with enough opportunity to share your views and feeling? If no, please feel free to elaborate.

3. Is there anything else that you would like to share with the researcher. **If the answer is yes and you would rather discuss them in person, please feel free to make arrangements with the researcher, Sarah Kelly at Email address here**
