Abstract

Children have difficulty with reading for a number of reasons. One of these reasons may be temporary conductive hearing loss (TCHL) in preschool, which can be caused by otitis media (persistent fluid build-up in the middle ear), one of the most frequent medical issues in preschool children (Burt & Schappert, 2004). While otitis media can be treated medically, the duration of hearing loss and the age at which the hearing loss occurred may contribute to future reading difficulties (Easterbrooks, Lederberg, Miller, Bergeron & Connor, 2008). The literature surrounding the connection between otitis media, TCHL, and reading development is inconclusive. In addition, the nature of interdisciplinary communication to discuss the potential future challenges for children who have had TCHL is unclear. Little is known about how professionals communicate with parents about these challenges, and about how parents can best support their children.

This research focused on providing detailed descriptions of how medical and educational professionals reported they communicated with each other and with parents about the potential reading risks associated with TCHL. This study followed standard qualitative research methods to conduct in-depth interviews with six medical and educational professionals and with two parents of children with TCHL. Results from this study have revealed important aspects that characterize what, when, and how professionals inform parents of children with TCHL about potential future reading problems. The knowledge gained through this research can guide future research and have practical implications for medical and educational professionals and provides recommendations for how parents are informed about potential future reading difficulties.
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Chapter One: Introduction

It is widely accepted that reading is a critical life skill: to gain employment, to receive further education, or to simply read the newspaper, reading is a basic necessity. While reading is a basic skill which is at the foundation of every child’s education, learning to read can be difficult for many children and the negative impacts can last a lifetime (National Early Literacy Panel, 2008). In Ontario, in 2009, 39% of Grade three students (i.e. 46,958 students) did not meet provincial reading standards (Education Quality and Accountability Office, 2009). The children who lag behind in reading skills typically receive less practice time, miss opportunities to develop comprehension strategies, and may develop negative attitudes about reading (Lonigan, Burgess & Anthony, 2000). These factors may all lead to what Stanovich (1986) termed the “Matthew effect,” where the separation between good readers and poor readers continues to widen over time, making it increasingly harder for the poor readers to learn in all academic areas.

While children have difficulty with reading for a number of reasons, one population that has been identified as having reading difficulties is children who are hard of hearing; these children are at risk of significant reading deficits (DesJardin, Ambrose & Eisenberg, 2008). The average deaf student gains only one third of a grade in reading each school year, and deaf students have an average of a fourth-grade reading level at high school graduation (Gallaudet Research Institute, 2003).

Although research demonstrates that children who have permanent hearing loss are at risk of reading difficulties, (Colin, Magnan, Ecalle & Leybeart, 2007;
Easterbrookes, Lederberg, Miller, Bergeron & Connor, 2008; Harris & Beech, 1998) the research is not as conclusive for temporary hearing loss (Golz et al., 2005; Teele, O’Klein, Chase, Menyuk & Rosener, 1990; Zumach, Gerrits, Chenault & Anteunis, 2010). One condition that can cause temporary hearing loss is otitis media. Otitis media is a fluid build up in the middle ear, which prevents the ear drum from vibrating properly, and persistent middle-ear fluid from otitis media can be a barrier to conducting sound (American Academy of Pediatrics, 2004). This condition is sometimes asymptomatic and parents do not always know it exists until substantial time has elapsed. While otitis media can be treated medically, the duration of hearing loss and the age at which the hearing loss occurred may contribute to future reading difficulties (Easterbrooks et al., 2008). Evidence suggests that children with recurrent otitis media during the preschool years are at risk of conductive hearing loss and speech delay (Eimas & Kavanagh, 1986; Hubbard, Paradise, McWilliams, Elster, & Taylor, 1985; Teele et al., 1990). A mild to moderate temporary hearing loss is common in children with otitis media. Mild hearing loss (26 to 40 decibels) can cause the soft sounds at the beginning of words to be difficult to hear and a moderate hearing loss (41 to 55 decibels) can cause most speech sounds to be difficult to hear (American Speech-Language-Hearing Association, 2010).

Although there is a growing research base examining temporary conductive hearing loss (TCHL), there is not yet widespread agreement about whether hearing loss due to otitis media has an effect on reading development. While there is extensive research showing a link between otitis media and reading development (Golz et al., 2005; Kindig, Richards, 2000; Loutonen et al., 1998), there is also research that disputes the connection (Lous, 1995; Schilder, Van Manen, Zielhuis, Grievenik, Peters,
Vandenbroek, 1993). Research is inconclusive about the connection between otitis media and reading development, but it is also unclear what medical and educational professionals in the field understand the connection to be. An additional issue that is uncertain is the extent and nature of interdisciplinary communication to discuss the potential future challenges for children who have had TCHL; that is, communication between the medical and educational systems, and within each system. In addition, guidelines for how the parents are informed about potential ramifications of TCHL for reading and how the parents can best support their children are also vague. Conductive hearing loss, even when it is temporary, is a more complex issue than it first appears.

**Purpose of the Study**

The purpose of the current study is to provide detailed descriptions of how medical and educational professionals report they communicate with parents about the potential reading risks associated with TCHL. In addition, the study will provide descriptions of how parents have learned to advocate for their children’s needs in the medical and educational systems. Two parents (from different families) and six professionals—three medical professionals, a speech and language therapist, and two teachers—provide their perspectives in individual interviews.

**Research Questions**

The driving question of this study is: from the perspectives of professionals and parents, how do the medical and educational professionals communicate with parents about the potential complications hearing loss can have on reading development? In addition the following questions will be answered:
1. What awareness do medical and educational practitioners report about the connection between hearing loss and reading development?

2. What specific knowledge do medical and educational professionals think parents need to have about the relationship of temporary conductive hearing loss to reading development?

3. What specific knowledge do parents report they need to have about the relationship of temporary conductive hearing loss to reading development? How is this knowledge currently made available to parents?

4. From the perspective of the professionals and the parents, what are the roles and responsibilities of each professional in supporting and educating children with hearing loss?

Definitions

While many terms have multiple definitions, it is helpful to clearly define key terms to help the reader understand how the author is using the terms. In the current research, hearing loss is defined as temporary conductive preschool hearing loss (TCHL). This refers to children who have had conductive hearing loss due to middle ear infections (known medically as otitis media) in preschool which has been treated medically. The length of time, and age at which the hearing loss occurred, may have contributed to future reading difficulties. Reading development refers to emergent literacy skills and to literacy skills, and includes phonological awareness. The term medical professionals, refers to all professionals who meet children in a clinical context. By educational professionals this researcher refers to all professionals who interact with children in the context of a school setting and its accompanying services. The speech and language
pathologist is referred to separately as this role can be included in both the medical and the educational fields.

**Research Context**

When I became a parent, I did not expect to have to advocate for my child. When my child was in preschool and repeatedly did not respond when I called her name, I knew something was wrong. My child had many ear infections in her young life, but they always resolved with medication. It was not until a visit to an ear, nose, throat specialist that it was confirmed the repeated ear infections had left my child with hearing loss (otitis media). Although surgery reversed the hearing loss, my daughter required years of speech therapy because her speech was impaired. This was the beginning of a long road. Along the way I had to learn to advocate for my daughter, to ensure she received all the help she needed but, throughout this process, I did not understand the potential future reading implications the hearing loss may have created. As a parent of a child, who had otitis media and experienced reading difficulties in school, I feel that I am in an excellent position to study this issue.

While my experience occurred some years ago, I believe this is a current issue for many parents, whose children have temporary hearing loss and who are attempting to understand the potential ramifications and the resources available. Burt and Schappert (2004) reported that in the United States between 1999 and 2000 there were 20 million visits to the doctor for otitis media, and more than 75% of the infections were in children three and younger. In addition, Segal, Leibovitz, Dagan and Leiberman (2005) reported that by the age of 1 year, 60% of children will have had at least one occurrence of otitis media, and 17% will have had three or more occurrences. Otitis media affects a
substantial number of children, and the potential ramifications of the infections are considerable.

It is the process of how professionals report they communicate with and inform parents of children with TCHL that is the focus in this study—the medical and educational experiences from the identification of hearing loss through to reading development. The process begins with the family physician and the parents. These two key players are typically the first to notice if there are chronic ear infections, and if there appears to be hearing loss. Either the parents approach the family physician with concerns or, during a doctor’s visit, the physician observes symptoms of concern.

In Ontario, a physician who suspects potential hearing issues can refer children to an audiologist or an ears, nose, throat specialist (ENT) for further tests. While the audiologist is referred to by the family doctor, they can also be referred to by an ENT. The audiologist can perform a variety of hearing tests and report the results to the referring doctor. The ENT specializes in diagnosing hearing issues and their causes. Once the condition has been diagnosed, the ENT can perform surgery to insert tubes into the children’s ears to allow any fluid build-up to drain, usually clearing any ear infections and reversing the hearing loss. After the ENT is satisfied that the hearing loss has been reversed to the best possible conclusion, the children may be recommended to see a speech and language pathologist (SLP) to address any speech impairments resulting from hearing loss.

In the Ontario system, the SLP works with children until it is believed no further help is needed, or until the children begin senior Kindergarten. If children require further
therapy, the parents are advised to seek speech and language therapy from within the educational system. In Ontario, after a parent has requested therapy through the student support teacher (SST), the children are added to the list to meet with a SLP within the school. As the wait lists at the school level are often long, the children may have to wait to be seen by the pathologist. In the meantime, the children attend a regular classroom. There is typically one pathologist and one assistant who provide services to a number of schools. In my experience, the children are taken out of class on an individual basis for half an hour each day for three weeks, three or four times a year. The children may need to work with the SLP for a few years depending on the severity of the problem. The SLP develops the program, and meets with the parents at the end of each year; the assistant runs the program for the children. Children are taught by a classroom teacher and those who experience learning difficulties may receive specialized teaching from a student support teacher. While there are many adult players in this long process, the key players are the family physician, the ENT, the audiologist, the speech and language pathologist, the classroom teacher, the student support teacher (SST), and the parents. These are the individuals whose perspectives are critical to beginning to develop an understanding of multiple perspectives on the possible connection between conductive hearing loss and reading development.
Chapter 2: Literature Review

This chapter reviews the literature on the relationships among phonological awareness, temporary hearing loss, and reading development. It discusses the hearing-to-reading knowledge base for medical and education professionals, interdisciplinary communication, and professional to parent communication as they apply to understanding the effects of temporary conductive hearing loss on reading development.

Phonological Awareness

It was once believed that reading began when children entered formal education; researchers now understand that reading is part of the continuum of language development which begins at birth. Lonigan, Burgess and Anthony (2000) suggested that an emergent literacy approach to reading development was more accurate than the previous approach which advocated that reading began in school. The emergent literacy approach views reading as starting to develop early in a child’s life, and encompassing the skills, knowledge, and attitudes that are developmental precursors to formal reading. Phonological awareness, alphabetic knowledge, and vocabulary have been reported as developmental precursors that form the foundation for reading words meaningfully (National Reading Panel, 2002). However, phonological awareness has drawn considerable attention in early reading success research, and has been viewed as the “strongest predictor of reading ability” after alphabet knowledge (Rayer, Foorman, Perfetti, Petsyk & Seidenberg, 2001, p. 38). Phonological awareness refers to “the ability to perceive and manipulate the sounds of spoken words” (Goswami & Bryant, 1990, p. 2), and to the explicit and deliberate processing of and acting upon those sounds.

The relationship between phonological awareness and reading is reciprocal, not
unidirectional. As phonological awareness supports early reading, skills (in reading) expand the development of phonological awareness (Cooper, Roth, Speece, & Schatschneider, 2002).

As the Goswami and Bryant (1990) definition of phonological awareness indicated, there is a close relationship between oral language and phonological awareness. These two factors create a solid foundation for later reading achievement in hearing children (Phillips & Torgesen, 2006). However, children who have hearing loss usually have receptive and expressive oral language impairments (Fagan & Pisoni, 2010; Harrison & McLeod, 2010), and phonological awareness becomes an issue. Studies that have looked at the outcomes of preschoolers who were diagnosed and treated at speech-language clinics indicated that preschoolers who had language impairment were at considerable risk of developing reading disabilities (Scarborough, 2001; Stothard, Snowling, Bishop, Chipchase & Kaplan, 1998). In a literature review of reading disabilities, Scarborough (2001) noted that “even when their early language deficits [had] lessened considerably in severity (or [had] disappeared entirely) by the time of school entry, children with...a history of early language impairment nonetheless remain at high risk for developing reading problems at a later age” (p. 102).

Lonigan, Burgess and Anthony (2000) examined the predictive power of emergent literacy skills for later reading skills in preschoolers. The findings from this study showed that phonological awareness grew substantially between 3 and 4 years of age indicating that the acquisition of phonological awareness could be time sensitive. Scarborough (1990) studied children two and a half years old to understand the possible precursors to reading deficits. The researcher observed that differences between children
who did and did not become disabled readers were evident at two and a half years. She noted that phonological productions were impaired in the children who later had difficulty reading. Scarborough stated that the causal relationship between the early symptoms and reading problems was complex and often indirect, but was nevertheless evident. The *Preventing Reading Difficulties in Young Children* report (Snow, Scarborough & Burns, 1999) came to the same conclusion that “the risk for reading problems is greatest when a child’s language impairment is severe in any area, broad in scope, or persistent over the preschool years” (p. 52). There are many experimental studies that indicate phonological awareness prior to formal reading instruction is causally related to later reading development for hearing children (Brady, Fowler, Stone & Winbury, 1994; Byrne & Fielding-Barnsley, 1991). There are also a number of studies that show a strong correlation between phonological awareness and reading success for children who are hard of hearing (Colin, Magnan, Ecalle & Leybeart, 2007; Dryer, McSweeney, Szczerbinski, Green & Campbell, 2003; Harris & Beech, 1998; James, Rajput, Briton & Goswami, 2008; Kyle & Harris, 2006).

Easterbrooks, Lederberg, Miller, Bergeron, and Connor (2008) conducted a study of 3 to 6-year-old children, and examined the development of emergent literacy skills of children, with hearing loss, over one school year. They found that scores of children with hearing loss on literacy tasks involving recognition of letter names were similar to scores of hearing children. However, scores on tasks which assessed phonological awareness showed that children with hearing loss lagged behind children with typical hearing (more than 1 standard deviation below the norm sample). Easterbrooks et al. (2008) is consistent with findings from Harris and Beech (1998), where researchers compared the
early reading progress of preliterate deaf children with hearing children. After one year of reading instruction, there was a significant difference between the reading gain scores of the deaf and of the hearing children (t (79) = 6.28, p < .0001). The deaf children also scored significantly lower than the hearing children on the phonological awareness task (t (79) = 3.31, p < .005).

Knowing that hearing loss has a causal relationship with oral language, that oral language is a strong predictor of phonological awareness, and that phonological awareness is a strong predictor of reading success, it is reasonable to conclude that a loss of hearing at a young age, could contribute to a reading deficit. The question that remains is if it is only permanent hearing loss that can contribute to a reading deficit, or if a temporary hearing loss during a critical developmental period can also be a contributing factor.

**Conductive Hearing Loss Due to Otitis Media**

Conductive hearing loss describes the condition when there is a barrier in the ear that prevents the eardrum from conducting sound. Otitis media is a medical condition which is known to create a barrier due to “the presence of fluid in the middle ear” (American Academy of Pediatrics, 2004, p. 1413). There are two forms of otitis media; otitis media with effusion (no symptoms of an ear infection), and acute otitis media (acute onset of symptoms such as fever and ear pain); however, because both forms can result in TCHL, this study refers to otitis media to mean the inclusion of both forms.

While otitis media has been researched in relation to various aspects of a child’s health and academic achievement, such as how it may affect mathematics (Luotonen, Uhari, Aitola, Kukkaroinen, Luotonen, & Uhari, 1997), and behaviour issues (Bennett, Haggard,
Silva & Steward, 2001), this study will focus only on those aspects that are concerned with TCHL and how TCHL is related to reading development.

Otitis media is the most common reason for young children to go to the doctor (Casby, 2001), and is most prevalent in preschool age children (Daly, Hunter, Levine, Lindgren & Giebink, 1998), with almost 90% of children having had at least one episode of otitis media by age 2 (Derosa & Grundfast, 2002) and 2.2 million cases diagnosed annually in the United States (Academy of Pediatrics, 2004). While many cases of otitis media resolve in a short period of time, others last longer. Casselbrant et al. (1985) showed that in 80% of preschool children with otitis media, it resolved within 2 months, leaving 20% of the children with otitis media that lasted longer. The Academy of Pediatrics (2004) agreed with Casselbrant et al. (1985) stating that “many episodes resolve spontaneously within 3 months, but ~30% to 40% of children have recurrent OME [otitis media], and 5% to 10% of episodes last 1 year or longer” (p. 1413). Golz et al. (2005) agreed that while hearing loss can be temporary, it can also persist for longer periods of time (between 6 to 12 months). It is this later population of children who may develop chronic otitis media, and may be at a higher risk of having hearing loss over extended periods of time.

Otitis media can be associated with a mild hearing loss (25 to 40 decibels) to a moderate hearing loss (41 to 55 decibels) (American Speech-Language-Hearing Association, 2010). As 18 decibels (or above) is needed to hear all aspects of speech clearly, a child with a 25 decibel (or higher) hearing loss, due to otitis media, could be at a disadvantage to receive all necessary information (Aithal, Yonovitz & Aithal, 2008). In addition, as the hearing loss is caused by fluid build up in the middle ear, it can fluctuate
with the varying level of fluid, and can be even more problematic than stable hearing loss (Golz et al., 2005) because it is inconsistent.

Regardless of extensive research demonstrating a relationship between otitis media in preschool children and later learning issues, there is controversy over whether the relationship is causal. Golz et al. (2005) acknowledged this controversy, and conducted a study to examine the relationship. The researchers invited 160 children ages 6.5 to 8 years old to participate, with 80 children having a history of otitis media, and 80 children without any history of otitis media. For a child to be included in the study group they must have had at least 10 episodes of otitis media before the age of 5, with prolonged periods of fluid build up and an average hearing loss of 25 dB or more. These children were matched with 80 healthy children from the same schools, and classes, of the same age, gender, and socioeconomic status. Each child performed five reading tests twice over a 2 year period. The results of the study showed students from the study group performed poorer than the control group, even though most of the students in the study group had restored normal hearing. It is interesting to note that those students from the study group, who still had conductive hearing loss, did not perform worse than the students whose hearing had been restored. The study concluded that “previous middle ear pathology, with the associated various degrees of hearing losses, was actually responsible for the impaired performance in reading found in the study group children” (Golz et al., p. 498).

The Golz et al. (2005) findings were consistent with the results of some previous studies (Luotonen, Uhari, Aitola, Lukkaroinen, Luotonen, & Uhari, 1997; Teele et al., 1990). Teele et al.’s (1990) longitudinal study followed 498 children from birth to 7 years
old. Using random selection the researchers tested 207 children from the original group as they turned 7 years old for intelligence, academic achievement, speech, and language. Using quantitative analyses the researchers examined the relationship between middle ear infections and scores on the tests that were administered. In the analyses the researchers controlled for other variables they thought to be possible predictors of the scores (e.g. gender and social economic status). In most of the tests there was a consistency of middle ear infection and lower test scores. The researchers concluded that otitis media “in the first three years of life was associated with ...lower scores in reading” (p. 689). The researchers questioned possible causes of this association and suggested that “persistent or fluctuating loss of hearing during critical periods of development may lead to later reduced ability” (p. 690). Findings from these two studies were in agreement with the Luotonen et al. (1997) study, which was a nation-wide, population-based random sampling of 1708 students in 119 schools in Finland. Through questionnaires sent to parents and teachers, students were evaluated and the relationship between the number of otitis media episodes in preschool and school achievement was measured. The researchers concluded that “early recurrent otitis media may have long-term effects on learning and attention skills at least up to the age of 9 years in spite of active treatment” (p. 50). The researchers found that children who had more than four episodes of otitis media before 3 years of age performed poorer in reading at age 9 than their peers who had fewer than four episodes. The researchers also indicated that otitis media had a more detrimental effect on the boys’ reading abilities than the girls in their study. This study supported Teele et al. (1990) that “otitis media before the age of 3 years had adverse effects on long-term consequences, but no association between otitis media episodes after
3 years and learning could be found” (p. 49). This differed from the finding of Golz et al., (2005) where the researchers concluded that it was during the first 5 years of life that otitis media episodes could adversely affect reading development. In all three studies the data suggested that effective interventions are needed to prevent the potential long-term consequences of chronic otitis media and “leave children free to reach their maximum potential for intellectual and linguistic development” (Teele et al., 1990, p. 693).

As previously stated, research literature is not consistent in the understanding of the relationship of otitis media to reading development. There are those researchers who found a connection between the two, and there are also those whose research concluded there was not a connection. Zumach, Gerrits, Chenault and Anteunis (2010) studied a group of 65 children who were assessed during the first 2 years of life and then again at 7 years of age. Parent questionnaires were used to obtain information about hearing loss during the time between 2 and 7 years of age. Using statistical analyses language scores were examined at the two ages in relation to the middle-ear status, while taking into consideration other possible factors (e.g. gender, breastfeeding, and education level of parents). The researchers concluded that they were unable to confirm whether or not otitis media had long-term consequences on language production and comprehension. They did note that hearing loss prior to 2 years of age had negative consequences on language development at 27 months, but no effect on the language of school-aged children. The researchers conceded that their sample size was small and larger studies would be needed to confirm their results. Lous (1994) analyzed 19 studies looking at the relationship between otitis media and reading ability, and concluded that the studies reviewed showed no correlation between TCHL and reading development. The researcher did concede,
however, that each of the studies presented issues in how they were conducted (how participants were chosen, whether otitis media was studied or TCHL was the focus, and if other factors such as socioeconomics were taken into account). Lous (1994) agreed that “a small proportion of ordinary school children might be expected to have middle ear disease [otitis media] and conductive hearing problems of a degree that would threaten their cognitive development and reading achievement” (p. 117). The researcher suggested there needs to be “more large scale, multi-disciplinary, multi-factorial” (p. 117) research conducted in this area before any conclusions can be reached.

As with the debate about the effect of otitis media on reading development, there is debate about the length of time that any detrimental effects of TCHL, due to otitis media, may last. Roberts, Burchinal and Zeisel (2002) conducted a study of 83 children who had otitis media and TCHL before 4 years of age. These children scored lower than their peers on language skills in preschool, but caught up to their peers by Grade 2. Likewise, Schilder et al. (1993) studied a group of 47 children and found a relationship between otitis media and language development in preschool, but the relationship disappeared by school age. Golz et al. (2005) studied 160 children, ranging in age from 6 to 8 years of age. Half of the children had a history of recurring otitis media before the age of 5 years, and half had no history of recurring otitis media. The children from each group were paired with each other based on being from the same schools, same age, gender, and socioeconomic status. Only children with at least 10 episodes of otitis media before 5 years of age and/or long-standing periods of hearing loss of 25 dB or more were enrolled in the study group. Along with hearing and neurological evaluations, the children were given five reading tests that were performed twice over a six month period.
The study group made an average of 15.2% mistakes on the reading tests compared to the control group which made an average of 5.8% mistakes. The difference between the two groups was statistically significant ($p < 0.001$). The researchers stated that “the difference in reading skills between the two groups can be attributed only to the presence or absence of early [otitis media] and not to other causes” (p. 498). In addition, the children who still had conductive hearing loss at the time of the assessments did not perform poorer than those with the history of TCHL, suggesting that it was the early TCHL that was detrimental to their reading development. The researchers recommended that otitis media should not be regarded as strictly a medical problem, but also regarded as an educational problem as it has reading ramifications.

In contrast, Bennett, Haggard, Silva and Stewart (2001) reported on a longitudinal study in New Zealand that had the objective of examining whether or not the effects of otitis media (including TCHL) were persistent into adolescence. The study sampled over 1000 children, performing assessments every second year from birth until the participants were 26 years old. Effects of TCHL on reading were reported in children up to the age of 15. The researchers recognized that their findings differed from Lous’ (1994) analysis of previous studies; however, they suggested an explanation for this difference might lie in the various case definitions and the use of different tests. The researchers also suggested that the size of the previous studies was too small to find effects, and that a study of 1000 participants would be “the minimum for showing effects” (Bennett et al., p. 94). Reading ability requires the use of various skills (including auditory skills), and these researchers have suggested that a possible reason for the long term effects of TCHL was “less efficient phonological coding” (p. 94). The nation-wide study in Finland (Loutonen, et
al., 1998) found similar results, where the researchers stated that effects from TCHL lasted until some children were 9 years old (even though they were receiving extra instruction in reading).

While the effects of TCHL due to otitis media are controversial in the literature, there appears to be more substantial evidence of an effect than not. It is clear that further research into the topic is warranted. Recognizing that preschool is the time when phonological awareness is known to develop (Lonigan, et al., 2000), and that perceiving sounds is critical to this development (Goswami & Bryant, 1990; Paden, Matthies & Novak, 1989), children who have had TCHL may be at-risk of not developing the required emergent literacy skills.

**Interdisciplinary Communication and Training**

While the research into phonological awareness and TCHL is important to understanding how to best help all children reach their potential, the implications cannot be put into practice without the professionals who work directly with children and their families. The knowledge of the issues involved, and of how the professionals’ roles fit into the bigger picture of a child’s growth and education, may make a difference in how successful a child is in acquiring the necessary reading skills.

**Collaboration between professionals**

There are many professionals in both the medical system and educational system that work with children with TCHL and their families, and that means they often have to work in collaboration with other professionals within their own system and across the two systems. Hartas (2004) defined collaboration as
...a dynamic system for educational efforts which endorse collegial, interdependent and co-equal styles of interaction between at least two partners...working together to achieve common goals in learning and decision-making process that can be influenced by personal, ideological and organizational factors. (p. 34)

Collaboration was viewed on a continuum where on one end there was the concept of cooperation (two or more professionals co-operated while remaining within their own professional boundaries) and on the other end was integration (where the “boundaries between different services and ideologies [were] removed altogether” (Hartas, p. 34)). While this literature reviews studies on cooperative collaboration between professionals, no studies were found which reported integration collaboration.

One issue that became apparent in researching the available literature on professional collaboration across the medical and educational systems was the prevalence of literature looking at collaborations between teachers and speech and language pathologists (Baxter, Brookes, Bianchi, Rashid & Hay, 2009; Gascoigne, 2008; Hartas, 2004; Law et al., 2001; O’Toole & Kirkpatrick, 2007), and the lack of literature on collaboration between teachers and other medical professionals, such as family doctors and ENTs. In many of the articles, the speech and language pathologists are referred to as medical professionals because they work in the medical system, not the educational system. Then inferences are drawn when researchers refer to the medical model, that suggest they are not only including the speech and language pathologists in the model, but are making a broader general application to the medical system.
Over the past 20 years, research in the fields of language development and literacy development has started to converge; the realization that language and literacy have a strong relationship has been well established. While research acknowledges the relationship, practitioners have been slower in addressing the need for a more interdisciplinary approach to address language and literacy difficulties (Snow, Scarborough, & Burns, 1999). Within the medical and educational systems there are many professionals who have a role in supporting children with hearing loss; the family doctor, the ears, nose, throat specialist (ENT), the audiologist, the speech and language pathologist (SLP), the classroom teacher, and the student support teacher (SST). As medical and educational professions become more specialized, the specialties form their own vocabulary, their own ways of communicating, and their own approaches to problem solving, which can reduce the opportunity for interdisciplinary exchange (Hall & Weaver, 2001).

Baxter, Brookes, Bianchi, Rashid and Hay (2009) examined various models of how teachers and speech and language pathologists could work together; the traditional model, the consultative model (Law et al., 2002), and the collaborative model (Wright & Kersner, 2001). In the traditional model the speech and language pathologists worked with a child one-on-one in a clinical setting. This model has increasingly been replaced by the consultative model because the former is very confining, taking place only in a clinical setting. In the consultative model, the therapist becomes a specialist who consults with the classroom teacher to provide information about, and rationale for, interventions. This creates somewhat of a hierarchy in which the teacher may be made to feel dependent on the therapist. In the collaborative model there is a two-way flow of information, with
each person seen as an equal partner, whose purpose is to combine skills and knowledge
to best help the children. With the collaborative model it is important to clarify roles and
expectations of each person, set clear objectives, and, for the systems that the
professionals work in, to support their efforts (Hartas, 2004).

Gascoigne (2008) presented a whole system approach to ensuring professionals
from the education and medical systems come together to provide the best care possible
for a child with a language deficit. This researcher discussed the legal framework that is
being focused on in Britain. This framework included issues such as: (a) supporting
parents by creating universal, targeted and specialist services; (b) early intervention and
effective protection, which focused on information sharing and common assessment
framework for all professionals working with a child; (c) accountability and integration
of all services and; (d) workforce reform to include a core of common skills and
knowledge for professionals working with children. The main concept of this whole
system approach was to have all services that related to children, regardless of profession
or medical or educational system, work together within their local area to help the
children achieve their potential.

Another issue Gascoigne (2008) addresses is the importance of speech and
language skills in all children. Speech and language pathologists have a key contribution
to make in supporting children with hearing loss, not only once the children reach school
age, but in pre-school as well (Gascoigne, 2008). For speech and language pathologists it
is no longer acceptable to claim that treatments of children with hearing loss have been
successful if the only improvement is in speech, because literacy development must also
be considered (Gillon, 2005). The speech and language pathologist is in the unique
position of bridging the medical and educational systems. They work not only in clinics, but also in school settings. Locality can be a strong asset as being physically in the clinic gives the therapist direct access to other medical professionals, and being in the schools gives the therapist direct access to the teachers and staff, and most importantly easy access to the children.

The *Education for All* (2005) report that was published by the Ontario Ministry of Education promoted professional learning communities. This referred to a school where staff was encouraged to work collaboratively. The model was expected to “ensure success in literacy and numeracy for all students, including students with special needs” (p. 53). While the document did not discuss professional collaborations outside of the school, it did encourage them within the school.

**Barriers to collaboration**

While the need for professional collaboration is evident, there are barriers to this working successfully. McCartney (1999) discussed a number of barriers to collaboration between medical and educational professionals. One group of barriers was called functional barriers, which included differing views as to who the services were being provided for; “all children for education versus targeted children for health, leading to pathology or deficit models of intervention” (p. 432), as well as different models of interprofessional interactions. Schools were considered an allocating service, where children received a fixed number of years regardless of their individual issues. The medical model was viewed as a commissioning service, where interventions were offered to targeted children when needed, and prioritized based on each child’s needs. Schools functioned with the belief that any deficit was not solely within a child, “they result from interactions
between the strengths and weaknesses of the child and the resources and deficiencies in the environment” (p. 434). The medical model however “assess[ed] a child, decide[d] whether there [was] a problem and outline[d] areas of strength and difficulties” (p. 434) on an individual basis. The difference between the systems was the focus of where the deficit lay, solely within the children or within the system as well as the children.

Hartas (2004) conducted a study to understand how teachers and speech and language pathologists collaborated. The researcher noticed that while the aims of the teachers and speech and language pathologists were the same (the best education for all students), their models for obtaining the aims were different. While the teachers were trying to facilitate learning in the least restrictive environment, such as including all children in the mainstream classroom, speech and language pathologists followed a more traditional medical model by looking at a child’s deficit as a reason to pull an individual, or small group of children, out of class. The medical model has the advantage of being able to focus on a small number of children at a time, to reduce distractions, and to address specific needs rather than the whole curriculum. However, the education model of inclusion in the classroom is sometimes at odds with the medical model. There is the view that while children are pulled out of class, they are missing important aspects of the curriculum that is being taught in class. In addition, being pulled out of class may segregate the children from their peers, and does not fit with the inclusive ideological trend in schools (Hartas, 2004).

Additional barriers to collaborations between medical and educational professionals have been reported. Wren, Roulstone, Parkhouse, and Hall (2001) reported that there was insufficient time available to create good quality liaisons between
disciplines. Law et al. (2001) stated that school cultures needed to recognize and value the importance of speech and language pathologists. Teachers reported insufficient support from speech and language pathologists (Dockrell & Lindsay, 2001), and a lack of professional education was also cited as a barrier to meeting the needs of children with hearing loss (Sadler, 2005). In addition, the staff involved had different employers, professional priorities, and locations (O’Toole & Kirkpatrick, 2007). Not only do the practitioners need to collaborate, but the systems themselves need to support these collaborations. Without the support of collaborative managerial teams, future positive development at the practical level is almost impossible (Gascoigne, 2008).

**Professional training**

The Ontario *Education for All* (2005) report stated that “...one of its most sobering findings is the evidence demonstrating the significant lack of progress that students with special needs in literacy...exhibit when not receiving a program based on research-supported instructional components” (p. 59). One way for programs to be research-based is for all staff involved in the education and development of children to be well trained. One aspect of research that has been revealed is the need for collaboration training.

Collaboration between professionals within and between the medical and educational systems can be effective if

...the professionals involved have a clear understanding of each other’s roles; where therapists are prepared to take account of the educational context; where teachers understand the importance of language to the whole curriculum; and where school systems support therapists’ involvement. (Law et al., 2002, p. 2)
Training programs for all professionals involved in the care and education of children with language issues have been recommended as the programs raise awareness, help to prevent communication problems, and provide knowledge and information relevant to help support children (Patterson, 2001). O’Toole and Kirkpatrick (2007) studied the impact of professional development workshops designed to provide educational and health professionals with knowledge and support, and to help preschool and school aged children learn to communicate. The workshops were based on the Weitzman (2002) program *Learning Language and Loving It* (LLLI). The participants took part in six video analysis sessions, and questionnaires and qualitative feedback were used to capture attitudinal changes. The researchers concluded that there were “significantly increased levels of linguistic and social responsiveness among education and health staff” (p. 345) at the end of the study. The questionnaire results demonstrated that participants viewed their skills as “significantly improved” (p. 342). While one of the goals of the study was to help preschool and school aged children learn to communicate, participants noted that their own communication style was improved. This finding is similar to Coulter and Gallagher (2001) whose study participants recognized changes in their communication styles as well as in the children they were working with. In relation to collaboration, the educators and therapists who participated in the study viewed collaboration as important. At the beginning of the study the participants’ definition of collaboration was unclear, but by the end of the study the participants listed collaborative factors as being “willingness to make professional changes and learn from each other, understanding each other’s roles, and sharing of information and
communication” (O’Toole & Kirpartick, 2007, p. 343). These statements are in agreement with Hartas’ (2004) definition of collaboration as previously described.

In Britain a joint government study was conducted in 1998 to understand the extent and nature of health and educational collaborations, and their ability to build partnerships with parents (Band, Lindsay, Law, Soloff, Peacey, Gascoigne, & Radford, 2002; Law, et al., 2001). The study surveyed and interviewed medical and educational professionals, as well as parents of children with speech and language difficulties. From this study 13 themes emerged, and 18 recommendations were derived. Included in these themes was the need for collaboration between health and educational professionals, and for a clearer understanding of their own and of each other’s roles. This need for clearer understanding of roles is not only between the medical and educational systems, but also within each system. The Law et al. (2001) study further acknowledged the need for continuing professional development, as participants in the study expressed a concern that there was insufficient knowledge about various aspects of speech and language development. An additional theme from the Law et al. (2001) study was the role of parents and caregivers. Although parents generally wanted to be active participants in their children’s medical treatment and education, they often felt frustrated and in conflict due to the perceived lack of collaboration between the health and educational systems. The parents reported feeling the most satisfied when they perceived the two systems to be working together.

**Parental Knowledge and Advocacy**

Parents are becoming increasingly involved in their children’s education, especially when the child has a potential disability. As parents’ participation expands,
their roles include “information seeker, problem solver, committee member, public educator, potential activist and, most importantly, spokesperson for the needs of their children” (Minnes, Nachshen & Woodford, 2003, p. 665). Because parents are the consistent adults throughout their children’s time in the medical and educational systems, they can offer consistency of information regarding their children that may not be available from any other source. In order to advocate for their children, parents need to become aware of the issues surrounding their children’s education.

Lindsay and Dockrell (2004) conducted a study of parents and teachers of 69 students who were 8 years old, to better understand what parents of children with speech and language difficulties viewed as the issues in meeting their children’s educational needs. The parents in the study were key people in the initial identification of their children’s problem, and they had a strong understanding of what their children’s strengths and weaknesses were (as was evident by the high agreement between the parents’ perspectives and the standardized measures). One of the concerns that parents expressed in the study was that they did not feel listened to by the professionals. Lindsay and Dockrell (2004) also stated that the parents interviewed felt ill-informed about how their children’s needs were being met. Some parents reported being involved in the identification process, but “decisions on the nature and extent of the provision generally remains in the domain of professionals, unless parents were prepared to fight for what they felt was appropriate” (Lindsay & Dockrell, 2004, p. 233).

Hixson, Stoff and White (1992) reported that there was an increase in advocacy training for parents, of children with disabilities, as research had recognized the effectiveness of parents as advocates. While the program the researchers discussed was
focused on children with chronic health impairments, the advice regarding advocacy training could be applicable to any parent who needs to advocate for their children. The goals of the program described by Hixson, Stoff and White (1992) suggested “training parents to use advocacy skills such as conflict resolution, communication, and assertiveness skills... [and to] develop a plan of action to achieve their individual goals” (p. 113). In addition, for parents to advocate for their child, the parents must be informed regarding their children’s issues. Parents of children with TCHL may not realize that their children could be at a higher risk of having a reading deficit. After the surgery corrects the hearing loss, and the speech therapy improves the children’s speech, parents may believe that the problem has been solved, which in many ways it has. They may not know their child is still at-risk, and may not know to advocate for them, resulting in potential early interventions being missed.

Early intervention could be further jeopardized as the parents are unlikely to inform the classroom teacher of early hearing loss, because the problem has been corrected. Therefore the teacher may not know this potential root cause of any possible reading deficits, or that the child should be observed from the earliest stage for evidence of any risk. The child’s reading difficulties may be put down to simply a developmental issue and, as a result, critical time could be missed that could have been used to strengthen a weak foundation in phonological awareness. The No Child Left Behind Act (2001) in the United States stated that parents of children who are eligible for an individual education program (IEP) needed to fully understand the various testing and educational options available to their children, and to be informed of the potential consequences. For example, parents should know about the school board policy on allowing children to
graduate high school with regular diplomas if the children have completed modified educational programs. In an attempt to inform parents about the options available, a parent advocacy brief was created by the National Center for Learning Disabilities. In the brief, options were outlined explaining who would be eligible, and how the options would be implemented (National Centre for Learning Disabilities, 2001). This is one forum for enhancing parental education and advocacy.

In a Canadian study, Law et al. (2001) stated that although many parents of children who had speech and language issues felt that they were served well by professionals involved with their child’s care, there were those who were frustrated by the experience. Collaboration between medical and educational professionals became an issue to parents when they felt that the professionals were not communicating clearly with the parents and with each other, and that things were not running smoothly. The study indicated that parents felt that when their children were not receiving the required resources, or communication was not open, they had to fight for the limited resources, and those parents who were literate and vocal were more likely to win than were parents who were less well informed. In reporting interviews with parents, Law et al. (2001) noted that while parents emphasized the importance of early intervention, they were often reluctant to approach doctors, and later teachers, with their concerns regarding their children. Parents did not feel that they were involved in a partnership with the schools or doctors, and they did not find information about learning issues to be accessible to them.

Both the professionals and the parents agreed that training for parents to support their role in a medical and educational partnership would be ideal (Law et al., 2001). Parental training might help bridge the distinction between professional knowledge and
parental knowledge of the children, because currently medical staff, education professionals, and parents may approach the needs of children from different perspectives. While the medical staff may be concerned with increasing language skills, the educational professionals want to facilitate children’s ability to access the curriculum, and the parents are trying to remove obstacles to their children’s access to society (Law et al., 2001). Both health and educational practitioners expressed the need for clearer definitions of their roles and responsibilities in creating a more transparent process for parents.

**Aim of the Study**

This literature review has demonstrated that phonological awareness is an important precursor to reading ability, and that it begins to develop during the preschool years, making that time in a child’s life critical. In addition, the literature has shown that TCHL due to otitis media is a potential factor in reading development. While the literature was equivocal, it raised the question as to what should be done to help children with TCHL. In addition, the review questioned not only the knowledge base of TCHL research, but also that of professionals who interact with children with TCHL. The research has also highlighted that multidisciplinary teams, who collaborate in supporting and educating children across medical and educational systems, must create a strong whole system approach to helping children with TCHL. In addition, parents advocating for their children can create a potentially strong ally in any intervention team.

This literature review has outlined the elements in the relationship between TCHL and reading development; however, there are still gaps in the research. While there is a great deal of literature that studies collaboration within the education system, and
between education and speech and language pathologists, there is little that studies
collaboration between education professionals and other medical professionals, such as
family doctors, or ENTs. In addition, as the research on otitis media and TCHL is
controversial, it is unclear how practitioners are interpreting this research and
incorporating it into their professions and responsibilities. How the professionals interpret
the research could be expected to have a great impact on what, if anything, they
communicate to the parents about otitis media and TCHL, and this would then impact
how parents advocate for their children. All of these factors contribute to how children
with TCHL are supported in their education to reach their full potential.

This study aims at better understanding of the knowledge of professionals in both
the medical and education systems about the issues surrounding TCHL in relation to
reading development, how this knowledge affects their practices, and what information
they share with parents of children with TCHL.
Chapter 3: Methodology

This study used qualitative research methods as this was exploratory research. The researcher wanted to better understand the knowledge, thoughts and practices of a select set of professionals and parents involved with children with TCHL, because they were rich in information about different parts of the process a child with TCHL may go through, and may provide meaningful insight into the process. The qualitative method was used to provide these insights “without being constrained by predetermined categories of analysis,[so to] contribute to the depth, openness, and detail ” (Patton, p.14 2002) of this study. The literature on the potential process children with TCHL may go through was extremely limited, so the researcher did not have previous research to build upon. The use of rich narrative descriptions of the participants’ experiences provided an in-depth view of their current knowledge and of the practices they encountered to communicate with parents. Such accounts may contribute to enhancing collaboration between medical and educational professionals and to better experiences for parents and their children with TCHL.

In this chapter the researcher describe the methodological steps used in this research study. This chapter includes a description of participant selection, recruitment strategy, the interview settings, data collection procedures, the interview process, the procedures for data analysis, ethical considerations, and ensuring the quality of the data.

Participant Selection

It is the process of communicating with and educating parents of children with TCHL that is the focus in this study; that is, the medical and educational experiences from the identification of conductive hearing loss through to reading development. It was
not the aim of this study to create a multi-perspective study of one case; rather the aim was to study the same phenomenon from different perspectives using a wide variety of experiences. Therefore, the participants in this study were not chosen to discuss their knowledge of the same case, but rather to discuss their experiences and knowledge of temporary conductive hearing loss and reading development in general.

This study used purposive and convenience sampling in participant selection. Many of the participants were busy professionals who had limited time to participate in a study. Therefore, to make participant selection more straightforward this researcher did not restrict the study to participants associated with one child. Purposive sampling was also used to invite only key people, who were involved in the phenomenon of TCHL and reading development, to participate in the study. This was also convenience sampling as described in the next paragraph.

The investigation took place in a medium size city in eastern Ontario, accessing one hospital, one school board, and a public health unit. As recommended by Gay and Airasian (2003), the researcher used her experience and prior knowledge to identify criteria for selecting the sample. The selection criteria were as follows: a family physician, an ear, nose, throat specialist (ENT), an audiologist, a speech and language therapist (SLP), a classroom teacher, a student support teacher (SST), and two parents of children with TCHL (from different families) who were willing to be interviewed.

The three medical professionals who were included in the study begin the process of identifying a hearing loss. Because the family physician is responsible for tracking a child’s developmental progress, this professional would usually be the first to notice how
often a child has ear infections and whether these infections may be causing a potential hearing loss. It is by this professional that a child would be referred for further testing. The ENT was included in the study because he is the specialist that a child is referred to due to chronic ear infections in this region under study. It is the responsibility of the ENT to decide what, if any, testing the child needs, including ordering and interpreting audiology reports, and he is also responsible for performing the otitis media surgery if needed. The audiologist is responsible for testing a child’s hearing, and receives referrals for various hearing tests from both the family physician and the ENT.

In addition, a SLP was included in the study. This professional was included because her role in supporting and educating the child who has had a hearing loss is critical. The speech and language specialist not only aids the child in speech and language development, but is the only professional role in which some individuals work in the medical system and some in the educational system. In this capacity the speech and language pathologist is in a unique position to understand both systems.

Other key players in this process were the teachers. For this study the researcher included two teachers—one classroom teacher, and one student support teacher—each of whom play a different role in the education of a child with TCHL. The perspective of the classroom teacher was critical because the classroom is where the child spends the majority of his or her day, and how the classroom teacher interprets a potential reading difficulty is important to a child’s reading development. It is the classroom teacher who may encourage, or discourage, the parent and child to seek further help. In addition, the student support teacher is the professional who helps decide what, if any, additional resources a child with a reading difficulty may need in the school.
The final key players in this study were the families of children who have had TCHL. One parent from each of two families was interviewed for this study because this completed the picture of all the key people involved in the children’s development. As the parents are one of the target audiences for this study the researcher felt that it was important to include their perspective. The two parents who participated in the study had their children enrolled in French Immersion schools. Many children in Canadian schools are enrolled in French Immersion and otitis media is very common in young children, so these children were representative of many children in Canadian primary classrooms. The researcher recognized, however, that it was possible that having to learn two languages exacerbated the children’s challenges in learning to read.

**Recruitment Strategy**

A phone call was made to a family physician, an ENT, and a SLP, known to the researcher (see Appendix A for sample script), briefly explaining the study, and requesting a meeting with each of these professionals. In each meeting, a letter of information was presented to further explain the study and the time commitment (see Appendix B). After the ENT agreed to participate in the study, he suggested that an audiologist would be a good addition to the study, and gave the name of an audiologist to contact. After the researcher contacted the audiologist, she agreed to participate in the study. Through prior personal knowledge of families who had children with TCHL, the researchers approached a number of families to invite them to participate in the study, and they were given a letter of information. The first two families to respond to the request, and who fit the criteria, were invited to join the study. While the researcher offered the choice for either parent in each family to participate, in both cases it was the
mother who agreed to be interviewed, stating that she was the primary caregiver. During the researcher’s volunteer work at an elementary school, a primary teacher and a student support teacher expressed an interest in the topic being studied, and were then each approached about joining the study. They were given letters of information inviting them to participate in the study. All participants were asked to sign a letter of consent (Appendix C). All professionals were invited to join the study not to discuss one particular child, but to discuss their knowledge and practice pertaining to children with TCHL in general.

**Interview Settings**

The interview with each participant was arranged at a location of their choosing and at a time that was convenient for them. The interviews with the medical professionals occurred in their private offices, with the exception of the ENT whom the researcher met in a staff lounge. The interview with the family doctor took place in one of her patient examination rooms. While the letter of information indicated that the interview would be 45 to 60 minute in length, the doctor had only 30 minutes to offer prior to the lunch hour, because she was needed at the hospital to see one of her patients. The doctor used her computer once during the interview to look up statistics on the prevalence of otitis media, while the researcher sat to the side of the computer. While the room was private, we were interrupted once by a staff member with a patient inquiry. The researcher adjusted the research questions to fit the interview into the shorter time allocation for the doctor.

The interview with the ENT took place in a private staff lounge, adjacent to his office. The lounge was a fairly large room with leather couches and a coffee table. We were the only people in the lounge, and we were not interrupted. The interview took
place mid-morning, and the ENT indicated this was his office time (as opposed to clinic time), and therefore he had time for the interview.

The initial interview with the audiologist was postponed due to a staff emergency, and was rescheduled to a later date. We met in her office and she referred to her computer and hard copy files during the interview to clarify some of her answers. The interview took place in the morning, which she indicated was her scheduled office time.

The speech and language pathologist (SLP), who worked in the community health unit, invited the researcher to her office for the interview. She had made some notes prior to our meeting on items that she thought might pertain to the interview. During the interview the SLP referred to her computer, her notes, and some hard copy files to clarify some of her answers. After the interview ended, she offered to show the researcher some websites on her computer that she thought might help with the research.

While interviews with the medical professionals occurred primarily in their offices, the two teachers who were interviewed had to find space. After meeting the student support teacher in her office at her school, we decided not to meet there because it was also the photocopy room and did not offer much privacy. We chose instead to use the principal’s office for the interview, because he was not using it. We sat at a boardroom table on one side of the office. Although the door was closed during the interview, a number of students knocked on the door looking for the principal and a staff member came in once.

The interview with the classroom teacher took place after school as she did not have time during the day due to her teaching schedule. We met in her classroom, with the
door closed. We sat beside each other at her desk, as this offered adult size chairs to sit on. The interview was interrupted once by another teacher looking for classroom resources.

Each of the parents chose a different venue for our meeting which appeared to depend on their availability during the day. The first parent who was interviewed chose to meet at her home as she was a stay-at-home parent. We carried out the interview at her kitchen table, where she had made tea and a snack. The interview was relaxed and conversational because the parent indicated she had no time constraints. The second parent to be interviewed was a nurse, and we met during her lunch hour at a meeting room she had booked through the organization where she worked. While she was on her lunch hour she indicated that she was not in a rush, and had made arrangements for an extended period if it was needed.

**Data Collection Procedure**

The researcher met with each of the participants individually and conducted a semi-structured interview. Each interview lasted between 45 to 60 minutes, with the exception of the family doctor’s interview which lasted 30 minutes. To ensure reliability of data, each interview was audio recorded using a hand held digital recorder.

To ensure the anonymity of each participant the following procedures were followed. The audio tapes were kept in a locked filing cabinet at the researcher’s home, and no copies were made. The audio tapes were listened to only by the researcher. The researcher transcribed each interview verbatim, and pseudonyms were used for each of the participants. The pseudonyms were stored in a separate location from the interview
tapes and notes. All notes were kept in a locked filing cabinet in the researcher’s home, and computer files were password protected. At the end of the study all audio, paper and computer files (outside of the thesis itself) were destroyed in a manner that ensures confidentiality of the participants to the extent possible.

**Interview Process**

Interviews were conducted with eight participants: family physician, ENT, audiologist, SLP, classroom teacher, SST, and two parents from separate families. The interviews were semi-structured, face-to-face, and individual with each participant. The semi-guided question format allowed for some pre-determined, open-ended questions designed to elicit specific information. Patton (2002) suggested that “an open-ended interview... permits the respondent to describe what is meaningful and salient without being pigeon holed into standardized categories” (p. 56). Probes were used to clarify information that arose from the participants’ answers. (See sample questions in Appendix D). The final question in all the interviews was “Is there anything that I haven’t asked you that you wish I had?” This was asked to ensure that all pertinent information had been obtained, and to give the participants an opportunity to share any final thoughts.

The parents were the first participants to be interviewed, because the researcher wanted to learn from their interviews whether there were any additional questions that should be included in the professionals’ interviews. The researcher then interviewed the medical professionals: the family doctor, ENT and audiologist, in that order. To gain a better understanding of the whole process a child with TCHL goes through, the researcher decided to interview the professionals in the same order a child with TCHL
might see them. After the medical professionals the SLP was interviewed, followed by the student support teacher and then the classroom teacher.

**Data Analysis**

The transcriptions of the interviews were used as the source for data analysis. Prior to beginning analyses, the transcripts were compared against the audio-tapes for accuracy, and the researcher listened to the audio-recordings numerous times to become familiar with the data. A cursory analysis of the data was done by hand, using coloured highlighters to identify codes, so the researcher could further understand the data. The interviews were then downloaded into the computer program ATLAS.ti to aid in combining the codes into a more manageable number. The computer program was useful in combining codes to reflect the data more accurately, however as this was a new computer program for the researcher it created issues of ease of use, and the researcher returned to finish the data analyses by hand.

The researcher used inductive analysis to create categories within each interview. “Qualitative inquiry is particularly oriented toward exploration, discovery, and inductive logic.... [and] begins with specific observations and builds toward general patterns” (Patton, 2002, p. 55-56). Each interview was analyzed inductively and codes, categories, and themes were generated for each. In the initial analysis approximately 80 codes were created for each individual interview. After further analysis, codes which were striving for the same information were combined (i.e. communication methods and communication struggles were combined into one code called communication). Some codes which were interesting, but not relevant for this study, were dropped (i.e. children’s emotional development). After combining codes there were approximately 48 codes
which combined into 16 categories, and approximately five themes for each interview and six themes for the cross-case analysis.

After the interviews were all analysed individually, a cross-case analysis was then performed on the interviews to look for patterns among all the interviews. The cross-case analysis was performed by hand, again using coloured highlighters to identify common themes. Patterns that were consistent between participants and patterns that were unique to each participant were recorded. The data were reported for each interview in narrative form. Then the data from relevant interviews were used to answer the specific research questions: What awareness do medical and educational practitioners report about the connection between hearing loss and reading development? What specific knowledge do medical and educational professionals think parents need to know about the relationship of hearing loss to reading development? What specific knowledge do parents report they need to know about the relationship of hearing loss to reading development? Where is this knowledge currently made available to parents? From the perspective of the professionals and the parents, what are the roles and responsibilities of each professional in supporting and educating children with hearing loss? Finally, all the interview data were used to answer the driving question: from the perspectives of professionals and parents, how do the medical and educational systems communicate with parents about the potential complications hearing loss can have on reading development?

**Ethical Consideration**

This research adhered to strict ethical guidelines (Patton, 2002). Prior to any research being conducted a proposal was submitted to the General Research Ethics Board of Queen’s University for ethical clearance, and clearance was received (see Appendix
E). After receiving consent from all of the participants, the ENT encouraged the researcher to include an audiologist in the study, which this researcher agreed was an important addition. A Research Ethics Change Form was submitted and approved (via an email). Letters of information were sent out prior to the interviews to ensure all participants were well informed regarding the study. Written letters of consent were discussed, presented, and signed by all participants prior to their participation in the study.

**Quality of the Data**

A number of strategies were used to ensure the quality and trustworthiness of the data and of the data analyses (McMillan & Schumacher, 2010; Patton, 2002). Each interview was recorded using an audio-digital recorder, and transcribed verbatim by the researcher. In addition, field notes were taken during each interview to safe-guard against loss of data due to technical difficulties and to record non-verbal communication of participants. This helped ensure that the information gathered by the researcher was as accurate as possible. The researcher’s personal experience with this phenomenon, and background as a teacher, contributed to the researcher’s understanding of the process and of technical jargon used (Strike, 2006).

While personal experience aids in understanding the process, this researcher made every effort to put her own perspective to the side and focus on reporting the perspectives of the participants in the study. As House (1977) stated, “He [the researcher] must be impartial rather than simply objective” (p. 45). While having used all of the methodological tools outlined in this chapter, the researcher’s aim in chapter 4 was to allow the voice of each of the interviewees to come through. It is only by hearing their
perspective on the issues surrounding hearing loss and reading development that themes were revealed in each participant’s interview and across participants’ interviews.
Chapter 4: Findings

The purpose of the current study is to provide detailed descriptions of how medical and educational professionals report they communicate with parents about the potential reading risks associated with TCHL. In addition, the study provides descriptions of how parents report such communication takes place and of how parents advocate for their children’s needs in the medical and educational systems. It is important to remember that the participants were not discussing the same case, and all but the parents drew on the participants’ extensive range of experiences that are applicable to more children than the discussion of one case would allow. This chapter reports the results of the eight participants who were interviewed, followed by a cross-case analysis. The order of the analysis is: Sonia (the first parent), Bethany (the second parent), Dr. White (family physician), Dr. Miles (ears, nose, and throat specialist), Patricia (audiologist), Sharon (speech and language pathologist), Olivia (student support teacher) and Frances (classroom teacher). Each of the participants was referred to by the title that they introduced themselves to this researcher. The interviews with the two medical physicians were set up by one of their staff members, and the staff member referred to them as doctor, so this researcher followed their lead. For all of the other participants in this study, they introduced themselves by their first names, so this researcher has also referred to them by their first names. All names are pseudonyms.
Sonia (parent): “If I Can Make the Difference for Him I Will”

**Sonia’s Family Background**

Sonia was a stay-at-home mother who had three children, all boys. Although English was the primarily language spoken at home, Sonia’s husband spoke fluent French. All of her children have been educated in a French Immersion school up until this past year where her youngest son (Curtis) moved into an English program. All of her children have had episodes of otitis media, but it was Curtis who has had the most persistent episodes of otitis media and TCHL. Curtis was 8 years old when his mother was interviewed. He was approximately 7 months old when he had his first episode of otitis media. In his 8 years, Curtis has had more ear infections than his mother could remember, numerous perforated ear drums, and five operations to insert tympanostomy tubes into his ears. The tubes allow the fluid to drain out of the ear, preventing perforations, and are intended to restore hearing. Sonia started being concerned about Curtis’ hearing when he was quite young:

I would say when kids normally start talking, he didn’t. It was gestures, or he’d just communicate in other ways. He’d be yelling or screaming, and not pronouncing things. He was leaving letters out of things. It was like he was living in a bubble.

She also noticed that when Curtis watched TV “the TV was louder. He has always spoken in a very loud voice, and I would have to say ‘you’re yelling’. For a little guy, he’s been the loudest one.”
Five themes emerged from analyzing the interview with Sonia. The themes were: communication with medical professionals, communication with education professionals, communicating with other professionals, advocacy, and advice to other parents.

**Communication with Medical Professionals**

Sonia reported having seen many professionals about to Curtis’ otitis media and TCHL, both medical and educational. Her initial contact with her family physician was proactive due to Sonia’s family history; “…because there was a [family] history of ear problems with the [other] boys, she [family doctor] sent him to the ENT.” Curtis was 13 months when he first saw the ENT. Curtis had check-ups with the ENT every six months, and between appointments spent time at the children’s outpatient department, family doctor, and emergency department because of additional ear infections, and perforated eardrums. Sonia reported that she felt she had to convince anyone not familiar with Curtis that there was an issue before Curtis would be seen. For example, when visiting the children’s outpatient centre, Curtis did not usually present symptoms that were normally to be expected, “a triage nurse would look and say, ‘Well, he hasn’t a fever or any other symptoms’, and I’d say ‘well just trust me he needs to be seen,’ you just get to know.” While the ENT had performed five surgeries on Curtis to insert tubes, Sonia reported that she was the one who needed to initiate the procedure. “We know that the surgery works for him, so why aren’t we doing it?”

One issue arose for Sonia when Curtis visited the audiologist. He had regular visits with the audiologist at the same time as his 6 month check up with the ENT. Curtis would receive a hearing test of 20 words, or a couple of sounds, a test Sonia reported as only taking a couple of minutes. The audiologist reported to her that everything was fine.
Sonia was not pleased with the duration of the hearing test and felt it was inadequate to identify potential problems. She went back to her family doctor and requested a full hearing test, to which the doctor agreed. Curtis was 7 years old when he had the full hearing test. The results indicated that he was “within normal range. He bottomed out at some stuff, and some stuff is better. Their normal range I question, because we’re seeing all those [speech] things.” Sonia realized she was not the only one who recognized Curtis’ hearing problems, “[teachers] questioned his ability to hear things properly. Especially when there’s a lot of noise going on in the classroom, he’s not able to hear and decipher things.” Sonia was still concerned about Curtis’ hearing because his ear drum was now very thin due to numerous perforations, and one hole (from the tubes) had still not closed. The ENT indicated that Curtis may have to have a further surgery, in the next few years, to close the hole if it does not close on its own.

**Communication with Educational Professionals**

Sonia’s interaction with and support from the classroom teachers has differed from year to year, some being more supportive than others. In addition, Sonia recognized that even the teachers who were willing to help, didn’t always help in the best way; they did some of the work for him:

Depend[ing] on the teacher, some are very open and receptive to it, they would make choices in seating more geared to his needs and [do] what is logical, put him at the front so he can actually hear. And if he can’t hear you at some point ‘cause there’s a lot of fluid build-up, then he’d better be able to read your lips. It’s very simple to me, and to some [teachers] it wasn’t. Some just don’t get it. He’s small
and he’s very cute, so he’d got through by merits of “oh he’s so cute, we’ll just help him out, we’ll just do this,” which is not helping him in the least.

Sonia had regular face-to-face meetings with the teacher and SST several times a year, and realized that because teachers were busy and had a whole classroom of students to teach, she needed to remind teachers what the issues were for Curtis. She expressed frustration at the school system because it was “within the fourth year [of schooling] that we’re now figuring out that the child doesn’t know what a letter is,” indicating that Curtis did not know the sounds of all his letters.

Sonia moved Curtis out of the French Immersion school into an English school and held him back to repeat Grade 2 at the beginning of this school year. She felt that the differences in the languages were adding to Curtis’ frustrations with reading acquisition, and that by having him repeat the grade he would be able to build a stronger reading foundation. It was Curtis’ parents’ choice to make these changes, the school was willing to move him into Grade 3 and to have him remain in French Immersion. In addition, Curtis had been receiving one hour of daily private reading tutoring, in which he was removed from the school. The tutor had no connection with the school and was paid by the parents. The tutor used a reading program that Sonia described as “systematic and intentional” in how it taught reading.

Sonia was pleased with the results of the private tutor, the English program, and Curtis’ gains during the past year in reading. “I’m certainly very appreciative of the SST that guided us. [She] really took it upon herself to give us extra.” About the private tutoring program Curtis attended, Sonia reported that “It’s actually working for him, and
he’s succeeding now. It’s phenomenal, it’s [like] night and day. He’s got more confidence, he feels good about himself ‘cause he knows he can do it, and it makes sense to him.”

**Communication with Other Professionals**

Curtis was assessed by a SLP, but not in preschool. He was referred in Kindergarten by the SST, and received this attention in Grade 1. The SST recognized that Curtis was having difficulties in the classroom, and recommended he receive help with his speech. “He was behind on reading, he was behind on everything that had to do with the classroom, and he struggled with it. He struggled in Kindergarten with letters and sounds.” Curtis visited the SLP in Grade 1, once or twice, and then she wrote a report and discharged him. Although Sonia reported that there was a report, she did not describe any of the recommendations that might have been in the report. Sonia was disappointed that her son did not receive more help from the SLP, “there was no sort of continuing care on sounds or anything with her, [the SLP said] ‘you need to work with him more.’ It was the assessment only.” The SST worked with Curtis on letter sounds and reading development, and also arranged for volunteer parents at the school to work with Curtis.

**Advocacy**

Sonia was a strong supporter of parents advocating for their children. She recalled needing to advocate for Curtis with almost every professional, in both the medical and the educational systems. With the family doctor she had to request a more detailed hearing test, with the ENT she stood her ground for Curtis to receive surgery, and with the audiologist she had to insist on getting a more detailed hearing test. When
the audiologist questioned the need for a more extensive hearing test because they had already given him the shorter test and decided his hearing was within the normal range, Sonia replied:

I don’t think he is [within normal range]. That’s why I’m here, because I need to be his advocate, because we’re seeing things, the teachers are seeing things, and we’re getting nowhere. So, if I can make the difference for him I will. Anything I can do to make his life easier within the classroom, then I’m going to do it, that’s why I’m here.

Sonia also expressed frustration when talking with the ENT. She felt she had a strong understanding of her son and the issues he faces, but did not feel the ENT always took her seriously:

Sometimes I didn’t feel listened to. I’m around this child every day. You’re seeing this child for 5 minutes every 6 months. I’m not stupid; I know what I’m talking about. I’m hearing it from other individuals. I’m seeing it in the home. Just listen and then offer other resources. What can we do to help [Curtis]?

When interacting with the educational professionals, Sonia again felt she needed to advocate for her son. When she switched him to an English school, and held him back to repeat Grade 2, she did not feel supported by the school in that decision. The school “suggested to us that he be [moved up] to Grade 3 with an IEP [individual education program]—because we switched him from a French Immersion program to an English program—to which I said ‘not going to happen.’”
An additional concern that Sonia raised was the lack of communication between the medical staff and the educational staff. She expressed feeling that she was the intermediary between the two systems, and that it was up to her to remember all the details and pass them between the professionals. She expressed frustration at not having up-to-date reports to hand to each professional she dealt with that would explain what had happened to Curtis, and what his needs were.

**Advice to Parents**

Throughout the interview with Sonia, she repeatedly expressed that she was concerned that other parents may not know how strongly they need to advocate for their children. When giving advice to parents about advocating for their children in the educational system, Sonia suggested “going into the school and keeping on top of things and requesting regular meetings. Keep saying the same things over and over again.” Sonia expressed that while some educational staff might alert parents to potential hearing and reading issues the children are having, parents should not rely solely on the teachers’ observations. The parents need to know for certain what is happening with their children at school, and the best method of doing this is to stay in regular communication with the teachers.

In a similar manner, Sonia advised parents of children with TCHL, to be a strong advocate for their children within the medical system. She advised parents to understand that they as parents need to help their children receive the medical care they feel is necessary, regardless of whether the medical professionals are discouraging. Sonia suggested to other parents:
Don’t stop. If in your gut there is an issue, chances are there is, and don’t stop fighting for them. If you need to go around somebody, do it. Your family doctor’s there to help, ours was completely on our side. If the ENT isn’t doing what you need him to do, then there’s absolutely other avenues that can be explored.

Sonia expressed that while she understood “going around” a professional could be intimidating for parents, she felt that, at times, it might be necessary, and that their children’s well-being was the most important factor to consider.

In addition to advice for interacting with professionals, Sonia has some advice to share regarding parental attitudes towards their children’s abilities. Sonia advised other parents of children with TCHL that, “you’ve got to be open to it [problems], I think that’s the biggest thing as a parent. If you’re not, if you say ‘oh no, my child’s fine, you can’t be talking about mine, mine’s perfect’ then you’re not helping your kid.” Sonia emphasised the need for parents to have a realistic view of their children’s abilities. She felt that it was by having an honest view of their children’s strengths and weaknesses that parents could best advocate for their children.

Summary for Sonia

The prevailing message in Sonia’s interview was that she would do anything that would help her son. She felt that she had to advocate for her son with the medical professionals and with the educational professionals, and that it was only by her being a strong advocate that her son received the help that he needed. She went as far as to pay for private tutoring in reading when she felt the services being offered were not adequate. She appreciated all that the professionals did offer her son to support him with his TCHL
and with his reading problems, but she also knew she had a lot to offer and wanted the professionals to listen to what she had to say and to take her seriously.

**Bethany (Parent): “Let Me Explain it…Again”**

**Family Background**

Bethany was a mother of two children, a 7 year old boy and a 5 year old girl, and she was a full-time nurse. Although English was the only language spoken at home, both of her children were in a French Immersion school. Her oldest child, Joe, was in Grade 2, and has experienced otitis media and TCHL in preschool. There was no other family history of otitis media. Joe started having ear infections as a baby, and by the age of 18 months had his first set of tympanostomy tubes surgically inserted. Prior to the tubes he had a number of perforations in his ear drums. Joe has had 2 sets of tubes inserted. In addition, he has had his tonsils removed because of tonsillitis and periods of sleep apnea.

Bethany became concerned about Joe’s hearing after an appointment with the audiologist. She requested a referral from her family doctor to the audiologist and ENT after Joe had a number of perforations. He was tested by the audiologist when he was 5 years old and diagnosed with a mild hearing loss. He did not start talking until after his tubes were inserted, and then “improvements in [his] speech were really quite remarkable.”

Bethany reported that, even with her background, she did not appreciate the potential long term repercussions of Joe’s otitis media and TCHL. She was surprised when an ear infection resulted in Joe having his ear drum perforated within a number of
hours. “I always thought it would be something he’d grow out of, and it’s only now that I’m realizing he’s not outgrowing it at the same rate most other kids would.”

The same five themes that emerged from the interview with Sonia emerged from the interview with Bethany: Communication with medical professionals, communication with education professionals, communication with other professionals, advocacy, and advice to other parents.

**Communication with Medical Professionals**

Bethany expressed that she was very pleased with the level of communication she received from her family doctor, the ENT, and the audiologist. She thought that her nursing background helped the professionals take her more seriously. When discussing her interaction with the ENT she said:

> When I went in I was always well informed, and I went in with clear expectations, and he always listened and was very supportive of that, and he knew I wasn’t just coming out of left field. He knew I knew what I was talking about and respected that.

She felt that because her interactions with the medical professionals were always relatively short in duration and infrequent that the professionals had to rely on the parent for information.

> The one area that she expressed dissatisfaction with regarding the medical professionals was when she had to take Joe into the emergency department due to an ear
infection, and she had to explain numerous times, to various personnel, what her son’s problems were and what he needed:

Having to take him into emerg and having to justify to the residents and interns and even the staff doctors in the ERs that this is my son, this is his hearing problem, and he needs antibiotics now or he will perforate, and I really don’t want to go down that road again.

She understood that the doctors’ normal procedure was to wait and see, and not give antibiotics immediately. But as a parent, who felt she had a good understanding of how her son reacted to ear infections, she thought she should have been taken more seriously, “there were times when they refused to give him antibiotics even though I voiced my concerns quite clearly and he ended up perforating.”

Although Bethany’s background as a nurse made her aware of some of the issues surrounding otitis media, such as TCHL, it was only ever the ENT and audiologist who mentioned to her that there could be a hearing issue. They also suggested that the insertion of tubes might increase his speech acquisition.

**Communication with Education Professionals**

While Bethany was satisfied with how medical professionals communicated with her, she did not report the same experiences with educational professionals. Bethany expressed that when she raised concerns with any of Joe’s classroom teachers they did not take her concerns seriously. “The classroom teachers have really downplayed any difficulties he’s had, ‘oh, he’s a boy,’ ‘he’ll catch up,’ ‘boys are always slower than girls,’ a lot of it’s written off just to the gender difference.”
Bethany requested that the SST assess Joe and, after her assessment, Bethany reported that the SST said, “Yeah, there’s a few things there, but nothing to worry about.” When Bethany questioned what the “few things” were, she said that she wanted a report in writing, but never received one. The parents met with the SST and classroom teacher to discuss the assessment. However, the SST did not give the report to either the parents or the classroom teacher prior to the meeting. “We had our meeting without the assessment results [that] we had requested be available, and both of them were ok with that.” She did however see examples of his work. He was having difficulties with reversing letters, confusing letters with others, and was unable to decode words. The SST expressed that, because Joe was showing some signs of improvement, there was no need to intervene.

Part of Bethany’s frustration was that there was no educational plan in place for Joe, and she felt that the school’s expectation for what Joe was capable of were too low. Bethany reported that there were never any suggestions from the SST or the classroom teacher of strategies Bethany could use with Joe. She then took it upon herself to tutor Joe at home and that showed her that there were “huge red flags going up,” and that his reading was well below grade level.

Any meetings between the parents and the school, Bethany reported, were initiated by her. She felt that “any sort of concerns had always been one way from home into the school.” In addition, she reported that the classroom teacher never voluntarily made concessions for Joe in the classroom, such as moving him to the front of the class.
Bethany reported she felt that the teachers treated her as if she did not know anything, and as if they thought they knew the child better than she did. “The teacher is almost arrogant I would say, in some cases, where they don’t want to listen to the parent because they are the expert and they have the experience. They’ve seen this, they’ve done it all.” She questioned this rationale as the teachers saw the children mainly as a member of a group, where it was easy for children to hide behind stronger students. As a parent Bethany felt she saw her child more on a one-on-one basis.

**Communication with Other Professionals**

When asked about whether Joe had received any speech and language therapy, Bethany replied that he had not. She had inquired at the school about Joe receiving some therapy, but the school did not think that Joe had any speech difficulties, and suggested that if Bethany wanted to pursue it on her own she was welcome to. Bethany did not agree with their assessment. However, she mentioned that because Joe was in French Immersion he did not use some of the sounds that he did at home when he spoke English, so they may not have heard some of his difficulties with pronunciation. One example Bethany gave of this difference was the use of “the” that Joe was not pronouncing correctly. She worked at home with him on the various sounds he was having difficulty with and felt he was progressing.

Bethany chose to pay for a private psychological assessment for Joe, outside of the school system. She did not expect to find he had a learning disability, but she felt the need to know for certain what Joe’s challenges were so they could work on them. While she understood that this assessment was available within the school system, there was a wait list of over a year and she did not want to wait that long to identify Joe’s potential
learning problems. At the time of the interview Joe had received the psychological assessment, but Bethany had not yet received the results.

Advocacy

Bethany reported feeling that being an advocate was essential for her son getting the help he needed, in both the medical system and the educational system. Even though the majority of Bethany’s experiences with medical professionals were positive, she felt a lot of frustration in having to explain Joe’s circumstances to every new professional she met:

It has almost entirely been me on both fronts [medical and educational]. Both identifying the hearing problems, and seeking medical attention, knowing the criteria for intervention and pursuing it, taking the initiative and being very much an advocate for my child. Saying “he meets this criteria; this is what needs to happen.”

In addition, much of Bethany’s frustration has come from advocating for Joe within the educational system, and not feeling like she was being listened to and taken seriously. She expressed that she did not feel like her relationship with the teachers was a partnership. “Explaining over and over again to the teachers, within the same school systems, within the same school, the issues again, and again, and again, and they’re not changing, they’re not improving.”

When questioned about whether there had ever been any collaboration or communication between the medical professionals and educational professionals regarding Joe’s TCHL, Bethany replied that there had not. She did however hope that
after the psychological testing was completed that the psychologist would come to the school to meet with the SST, classroom teacher, and herself to discuss the results.

**Advice to Parents**

Bethany expressed that she felt it was critical for parents to be an advocate for their children, especially when they have conditions like TCHL that could contribute to learning problems. She would advise parents to:

Pay attention to it. It’s something that permeates a lot, a lot more than you would expect. I didn’t expect him to have reading issues. Pay attention to it. The hearing and speech transcends so many things that you don’t watch for.

Bethany went one step further and offered advice to the professionals. She praised the ENT and audiologist and said “great job, keep it up.” For the emergency staff she recommended that they “open their ears and pay attention to people, and listen to what their concerns are, don’t just cite the research because each person is an individual.” For the teaching professionals, Bethany suggested similar things as for the emergency staff. She wanted them to remember that although they have experience and knowledge, they should not lose sight of the individual, as she felt they had in her son’s case.

**Summary for Bethany**

Overall, Bethany felt that her concerns regarding her son were listened to by the medical professionals, and downplayed by the educational professionals. She felt that her nursing background put her in good standing with the medical staff, and that they took her concerns seriously. However, the educational staff repeatedly ignored what she had to say, or thought she was over-reacting. Bethany believed that parents need to be strong
advocates for their children. When, even by advocating, she was not satisfied with the services being offered she paid for private assessment, and stepped in herself to do remedial work with her son.

**Dr. White (family physician): “I Try to Be as Aggressive as Possible at Looking at What the Underlying Problems May be”**

**Dr. White’s Background**

Dr. White is a female family physician who works in a family health clinic. She has been a practicing doctor for 16 years with a medical background in family medicine, in obstetrics, and in emergency medicine. When interviewed, she was currently practicing family medicine in a clinic with three other family physicians. Dr. White related that she was trained to diagnose and treat otitis media not only through books and lectures, but also by hands-on experience:

You just learn that [diagnosis] by being supervised as an interning resident, usually over 2 years and you just do it, and do it, and do it, and do it, and an experienced doctor then says yes or no, and describes what they saw… it’s a hands-on thing that you learn by doing it.

In Dr. White’s practice she worked not only in her office during the week, but also in a walk-in clinic on Saturdays. In her practice during the week she estimated that she saw one child per day with otitis media, and between 10 to 15 children with otitis media at the clinic on a Saturday. She also indicated that it was a seasonal problem with a much higher incident of otitis media in the winter months. “It is often associated with a preceding viral respiratory tract infection so, when it’s cold and flu season, it peaks.” The
majority of her patients that she saw with otitis media were between 12 months and 4 years of age.

In the interview with Dr. White four themes emerged: communication with other professionals; communication between a professional and parents; advice to parents; and ways to improve the system.

**Communicating with Professionals**

One area of interest for this researcher was to look at how professionals communicate with each other. When Dr. White was asked how she communicated with other medical professionals, she discussed “referral notes, consultation letters, and replies.” Dr. White elaborated that if she suspected a chronic case of otitis media or any hearing loss in a patient she sent a referral to the ENT, and perhaps the audiologist (if the ENT wait-time was lengthy). If she suspected a speech and language issue she suggested that the parents take their child to the local health unit’s speech and language clinic. Dr. White further explained that for a patient to see a medical specialist (such as an ENT or audiologist) a written referral note had to be sent from a practicing physician, mandated by the Ontario Ministry of Health. The specialist then sees the patient and sends a written reply of the diagnosis and treatment. The one exception to this referral and reply procedure was when seeing the SLP at the health unit. This was a self-referral process in which parents could take their children to the clinic without a doctor’s referral. This is discussed further in the SLP section.

When asked for a specific example of a time when Dr. White collaborated with other medical professionals about a child with otitis media, Dr. White replied
“Collaborate? I think I always collaborate in that I work in a collaborative manner with ENT and pediatrics.” When asked what opportunities there were for working directly with other colleagues, outside of the referral process, Dr. White answered “none.”

During the interview the issue of collaboration between herself and educational professionals arose. Dr. White could not recall a time when this would have occurred. She noted that for severe cases she knew that the ENT had communicated with professionals from the educational system, and she would receive updated notes from him, but said that she was not directly involved with any staff from the educational system. The relationship between the ENT and the school system is discussed further in the ENT section.

**Communication with Parents**

When discussing how Dr. White communicated with parents, the idea of educating the parents was a recurrent theme. She described a spectrum of people who brought their children to see her, and said it ranged from those parents:

who bring their child in every time they get a fever because they’re afraid they’re going to get an ear infection and they want them put on drugs, [to the other end of the spectrum] where some parents don’t bring in the child unless they have severe symptoms for a week and they can’t hear at all and they’ve got pus and blood running out of their ears.

Although this was the spectrum, she did acknowledge that most parents were somewhere in the middle. Dr. White commented on how much time she spent educating parents on the difference between viral infections and bacterial infections, and how antibiotics only
worked for bacterial infections. She discussed the risk of using antibiotics every time as there “was a whole shift when we used to treat all ear infections with antibiotics, to treating only some ear infections with antibiotics, that took a lot of education.”

Dr. White encouraged parents to tell their side of the story to her. While she examined children for physical symptoms, she acknowledged that parents could fill in part of the picture that the present symptoms may not describe. While she supported referrals to specialists, she also commented that parents had a role to play in their children’s health because of their intimate knowledge of their children’s activities and their health issues from day to day.

**Advice to Parents**

The advice Dr. White reported she gave to parents of children with otitis media and TCHL was to be aggressive. “If tubes are offered, don’t be afraid of the minor surgery that’s involved in having tubes put it.” She tried to coach parents through the concerns that they might have regarding surgery, and stated that the benefits surpass any small risks that are involved.

Dr. White encouraged all parents, regardless of otitis media or TCHL, to spend time reading and talking to their children right from birth. She discussed the matter of screen time with them, and tried “to encourage them to read even to child[ren] who [are] really young, and [talked] about routine and games they can play with their child[ren].” All of these strategies were aimed at helping to develop emergent literacy skills.

Dr. White reported that she did not have a lot to do with children who presented reading problems once they reach school age, and that it was usually the school that took
care of the children at that point. When she did see the school age children for reading problems it was usually because they had a global delay (cognitive impairment), or children who did not have a reading rich environment at home. Dr. White discussed with the parent how the home environment had a strong impact on a child’s reading ability:

I strongly suspect the kid’s never seen a book, they don’t have a library card.

There are people, who take their child to story time at the library when the child’s 2 months old. Then there’s people who have the TV on the minute they get up in the morning and it’s on until the child falls asleep with the TV in their bedroom.

Ways to Improve the System

Dr. White discussed two main ways in which the system could be improved. The first way dealt with wait times. She commented on the fact that the wait times for children to see an ENT and audiologist were too long, and children need to be seen sooner to minimalize any potential complications that could arise from extended periods of otitis media or TCHL. An additional concern of Dr. White’s was that children may “fall outside of the system for getting speech and language therapy who then have to go looking for private funding. I think it’s ridiculous that [the parents] aren’t getting any funding.” The children would “fall out of the system” by becoming school age, when they would then have to seek speech and language therapy through the school system. However, the fact that the children could get help within the school system did not relieve Dr. White’s concern, because the educational system also had long wait times, and a lack of funding:
Some kids of school age get speech and language therapy once in a while at school, but it seems to me that unless [the parent] can pay privately, you are at a real risk of not getting enough service for your child.

**Summary of Dr. White’s Interview**

Overall, Dr. White believed that there needed to be more education provided for parents of children with otitis media. She explained how treatment of ear infections has changed over the years, and it had become part of her job to explain to parents what their options are. She believed that she worked collaboratively with other medical staff in providing care for her patients, and this collaboration took the form of referrals and reports. She also recommended that parents be aggressive advocates for their children. One of her main concerns about how the medical system and educational system operated was the lengthy wait times.

**Dr. Miles (ear, nose, and throat specialist): “I Think My Examination is Key”**

**Dr. Miles’ Background**

Dr. Miles had been a practicing ears, nose, and throat specialist (ENT) since 1989 after completing four year residency in Otolaryngology, and an additional year training in Pediatric Otolaryngology. He had a general practice in Otolaryngology with a major portion of his clinical time spent seeing children. One area of interest for Dr. Miles was the management of recurrent and chronic otitis media. In his practice, there were about three clinics a month for children. In these pediatric clinics, Dr. Miles stated that “it’s probably half to two thirds [that] are ear issues,” and that for the “vast, vast, vast majority
of people, ear issues come down to ear infections or Eustachian tubes problems,” which is what otitis media contributes to.

During the interview with Dr. Miles five themes emerged: understanding otitis media; communication with other professionals; communication between a professional and parents; advice to parents; and ways to improve the system.

Understanding Otitis Media

Dr. Miles was an ENT, with a particular focus on children and otitis media, so it was informative to discuss his understanding of the condition and how this was translated into his everyday practice. The first aspect of otitis media we discussed was the various types of cases he saw in children. He identified two separate types of cases that he frequently saw: “kids who get frequent infections, and their fluid clears right away, and their hearing is a very short lived issue, versus the kids who get all congested with fluid, and their hearing is a long term issue.”

Dr. Miles went further to explain the cases he saw on a continuum. The best case scenario was the children whose hearing clears right away and the worst case scenario he referred to as the “blue ear” and these are the children who typically had TCHL due to otitis media, and he explained what blue ear is:

It’s really thick, thick, mucus. There’s a whole blob of stuff in there that it’s really hard to hear through, and so a 35 to 40 decibel threshold you might see with that. It’s like wearing those little yellow ear plugs you can squish in your ears. Those are 35 decibels.
One of the main strategies that Dr. Miles discussed was the use of surgically inserting tubes in the ear drum to allow fluid to drain. He acknowledged that if left alone, the ear canals would eventually grow and the otitis media would clear up. However, he was very sensitive to the fact that it was the journey to get to the point of the ear canals growing large enough that was the difficulty. When a child had multiple episodes of otitis media, Dr. Miles became concerned that too much time was spent not hearing properly. “If someone has an infection every month and they’ve got blocked ears for a week or 10 days, and that’s happening a lot of the year, that’s a lot of the year where they’re not hearing properly.” In these cases he would recommend the insertion of tubes, especially in preschool children. There was a range of how often tubes needed to be inserted. Some children had only one set of tubes, while he had seen children who had six or seven sets inserted over a number of years:

You tend to lean more to tubes in that situation [chronic thick fluid in the ears] because you really can’t predict how long that fluid will stay and if they’re already having some issues at that critical developmental phase then we tend to look more, but it depends on the hearing thresholds, that’s a big determinate as far as tubes go.

Dr. Miles would continue to see a child every six months after the procedure unless there were problems between, and then he would see them more often. He would continue to see the child until the tubes had been removed, or had fallen out, and there were no longer problems of otitis media or TCHL. He would leave the patient’s file open for one year in case there were any further concerns or additional episodes of otitis media.
One of Dr. Miles’ concerns was that it was not always obvious when children had a hearing problem. He used the example of comparing a child’s nose and their ears. “If a person’s nose was misshapen it would be obvious, but with the eardrum, you can’t see it so it’s not always obvious that there is an issue present.” He cited a medical article which said that in a child the Eustachian tubes were “the width of 2 hairs,” which he used as an example of why it was so easy for the tubes to become blocked. An additional complication, in understanding if there was a hearing problem, was the fact that the children may not have known themselves that their hearing was poor and may have become accustomed to compensating for it:

That was one of the concerns…that kids may have this fluid there and nobody really knew they weren’t hearing, they may just have thought they were bored or thought they were tired. So that’s the tricky part about fluid in the ears. It may not be recognized, and it could lead to other issues.

Although Dr. Miles knew that there was some controversy over the use of tubes as a strategy to reverse the effects of otitis media and TCHL, he also heard the response from parents about the difference in their children’s hearing:

It is amazing how often, quite spontaneously, people will say “I can’t believe how much more my child is talking” …or they’ll be surprised how much their [children] are noticing [sounds] around the house they haven’t noticed, like the kid will be “what’s that noise?” and it’ll be the fridge that’s running, or the microwave beeping, or a train in the distance, but they haven’t heard those things.
Communication between Professionals

Dr. Miles’ main connections with other medical professionals, outside of his immediate office, were with family doctors, pediatricians, and audiologists. Dr. Miles confirmed what Dr. White addressed in her interview, that a written referral from a physician was required for a patient to be seen by an ENT. These referrals came from family doctors and pediatricians. When asked how severe the otitis media needed to be to be referred to an ENT, he stated that it depended on the family doctor’s comfort level. He did, however, suggest that “three or four ear infections in six months are considered a significant number.” His interaction with family physicians and pediatricians was based on a written referral request from the other doctors, and a written reply in the form of a report from himself back to the referring doctor.

While Dr. Miles interacted with the audiology department, and referred his patients to them, they cannot refer patients to him, because they are not medical physicians. Dr. Miles discussed that he had a more direct working relationship with the audiology department than his relationship with family doctors and pediatricians. He suggested this was because of the close physical proximity of the two offices, and because of the nature of their inter-related work. When interacting with the audiology department, he usually made a hearing test request in writing. This test was often performed the same day by audiology technicians and the written reports were sent to Dr. Miles immediately:

Our clinics have audiology technicians there to help us out so we can get the test done right away, and sometimes we’ll do a full hearing test depending on their
concerns or sometimes…we might just do the anagram test to try to move the ear
drum and see how responsive that is, as well as look at what’s called the speech
reception threshold… how quiet a sound can be repeated back properly.

Dr. Miles did not work with the health unit’s SLP. When he had a patient who
was having speech and language issues, he had mentioned the program to the parents, but
as the program was a self-referral process, he had not needed to be involved. His
understanding was that most parents had heard of the SLP program from their family
doctor, and his clinic had some speech and language brochures that the parents could pick
up. He did not receive requests from the SLP as referrals to his clinic could only be
requested by a physician. In a similar manner, Dr. Miles had very little interaction with
any professionals in the school system. “The odd time they [the school] ask for a copy of
the hearing test. Rarely, rarely, rarely [do] I ask for something.” The rare occasion that he
was talking about was usually for children with developmental delays beyond otitis
media or TCHL.

Advice to Parents

Dr. Miles wanted parents to understand “what the impact [of otitis media] is on
hearing.” He gave parents recommendations such as having their children sit in their lap
when reading to them so the children could hear with minimal background noise. He
wanted parents to understand that while children had diminished hearing, they could still
hear, so parents should keep talking and reading to them. He suggested looking for more
correctable problems, such as finding alternatives to daycare if the children kept getting
colds. He strongly recommended that there be no smoking in the house, or smoke on the
parents’ clothes, or anywhere near the children. “Studies have done tests where they’ve measured products of nicotine in kids’ blood streams and collated [it] with high levels of more infections.”

When discussing antibiotics, Dr. Miles suggested that they were not always needed, and that “there might be over diagnosis or over treatment” with drugs. While he would advise parents to curtail the use of antibiotics, he also mentioned that some medical professionals needed to be re-educated on the use of antibiotics for ear infections.

Dr. Miles gave additional advice to parents and teachers. He suggested that, when children were in a classroom, the adults need to be aware of giving children with TCHL “preferential seating, and getting notes” which were the same recommendations he would give someone with a learning disability. In some cases he had seen the audiologist work with the classroom teacher with a signal-to-noise ratio, and put in a FM system in the classroom to allow the student with TCHL to be able to hear the teacher despite the background noises of the classroom.

**How to Improve the System**

While Dr. Miles enjoyed his practice, he believed the system could be improved. One of the issues that Dr. Miles addressed was how busy his clinics were, leaving no flexibility if he needed to see someone quickly. He stated that it was not a matter of finding more time, but “we need more clinic rooms and more spaces to see people.” Due
to the specialized equipment required, acquiring more space would mean acquiring more equipment:

I’ve got a couple of referrals on my desk who are kids who’ve got hearing loss probably 30 to 40 decibel threshold and I’m [saying] “we’ve got to find some spots.” So they’re sitting there looming in front of me until I can create more time, or something happens so I can get them in. That’s not how it should be.

Summary of Dr. Miles Interview

The common thread that ran through Dr. Miles’ interview was his passion and knowledge about otitis media in children. Dr. Miles acknowledged that if left alone the ear canals would eventually grow big enough to stop the ear infections, but it was the time that was lost while waiting for the growing that was of concern to him. Dr. Miles believed while there may be some controversy over the use of inserting tubes as a strategy for otitis media and TCHL, the overwhelmingly positive response he heard from parents was undeniable. The main concern for Dr. Miles was the lack of opportunity he had to see all the children who needed to be seen in a timely fashion.

Patricia (audiologist): “We Can Expedite Things”

Patricia’s Background and Knowledge Base

Patricia was an audiologist with over 30 years experience in the field. She received her bachelor’s degree in communication disorders, and her master’s degree in audiology. She was currently the head of her department of six audiologist and three technicians in a hospital environment. Her caseload was about 30% children, and most of
them were preschool age. There were two main reasons children were referred to her department: frequent ear infections and speech delays. She also included behaviour issues as a reason children were referred to her, if there was concern that the behaviour was due to hearing loss, but this was not a frequent occurrence. Otitis media was the most common disorder that she saw in children, with the most cases occurring in the fall and winter.

Patricia discussed conductive hearing loss associated with otitis media, and while it usually was a temporary condition, she expressed concern at the duration of the hearing loss:

Generally the longer they’ve had it [fluid build-up], the more hearing loss they’re going to have with it, and there’s a sort of maximum conductive hearing loss that you can have and that would be up to around 50 decibels, which is significant.

Hearing loss was significant for children in any setting, but especially in the classroom where it was often quite noisy. Patricia estimated that a young student with normal hearing probably only hears about 50% of what is going on due to the level of noise in the classroom, and when a hearing loss is added on top of that, a substantial amount of information is missed.

When analyzing Patricia’s interview four themes emerged: communicating with other professionals; communicating with parents; advice to parents; and ways to improve the system.
Communicating with Other Professionals

Patricia explained that for children to be referred to audiology the Ontario Ministry of Health required the referral to come from a physician. The children typically saw their family doctor or pediatrician first who would “often send them here [audiology] to get the testing done so they know whether they want to take the next step to refer to ENT.” The referrals came in written form. Once the testing had been completed, the audiologist wrote a report and sent it back to the physician who requested it. The audiologist might see the children again to track their progress, or as follow-up after treatment by the ENT.

The ENTs also referred children to audiology, but it was often done as part of an ENT clinic. The audiologists worked quite closely with the ENT staff as they saw a lot of children for testing through the ENT clinics. It was usually the audiology technicians who performed the tests during ENT clinics, although the audiologist had to sign off on any reports. The ENT often received results from the technicians the same day; however, more extensive testing performed by the audiologist would take longer. There was a 2 to 3 month wait list for children to see an audiologist, which was about half the time of the wait list to see an ENT. This was another reason why some family doctors referred children to the audiologist before the ENT.

After the children had been tested by the audiologist, and the report had been sent back to the referring physician, a referral to an ENT might be recommended. Patricia said that “some family doctors would say ‘if you [the audiologist] think it needs to be done just go ahead and do it,’ but we really can’t. They have to send out a referral letter. But we can expedite things somewhat.” The audiologist could talk directly to the ENT and
the ENT may offer to ask the referring doctor to phone or fax over the referral and they would triage the children to the top of the list.

Patricia had worked with the SLP department at the hospital where she worked, but she had also suggested that parents take their children to the health unit speech and language program because its mandate was to treat preschool children. While this was a self-referral program and parents could contact the program directly, Patricia often offered to make the call for them if the parents seemed reluctant.

While Patricia had worked with the SST at various schools, it was only in cases where children were wearing hearing aids or sound field systems were required in the classroom. Although it was not common, Patricia had seen children with chronic TCHL who did not respond to other treatments, require hearing aids or sound field systems to help them until their bodies could grow enough to clear the otitis media. She worked directly with the SST to help manage any challenges and then the SST worked with the classroom teacher.

**Communicating with Parents**

Patricia felt that most parents who came through her office were concerned about their children’s speech, and they understood the connection between speech and hearing loss. Patricia reported that she did not assess or work with children’s reading problems: children were not referred to her because of difficulties with reading, but because of difficulties with speech and hearing.

Patricia was conscious of informing the parents about what was happening with their children when they had TCHL. Due to the fact that the hearing loss fluctuates,
parents often become frustrated because it seemed to them that the children were choosing not to respond, rather than not hearing. “Because conductive hearing loss fluctuates, the typical response [from parents] is ‘sometimes he hears me, sometimes he doesn’t.’ ‘He has selective hearing.’ I can see where they’re coming from.” She realized that for some parents it was difficult to understand, so she tried to educate the parents about what their children were going through. One of the strategies she used with parents was to take them into the sound room and simulate how their children were hearing so they could have a better sense of why the children did not always respond.

Advice to Parents

Patricia recommended to parents that they make sure their children received the treatment they needed; she suggested they contact their family doctor or pediatrician and request a referral to audiology or ENT if they thought there were any problems with their children’s hearing. Parents needed to understand that conductive hearing loss fluctuated so it could be tricky to diagnose. It might take visiting the audiologist a few times before they could get an accurate picture of what was happening with the children’s hearing.

In addition to getting professional help, Patricia discussed some things that parents could do to help minimize episodes of otitis media for their children. Preventative measures included making sure that there was no one smoking in the house or near the children, and reducing the number of pets if possible, as many children with otitis media also have substantial allergies. While she recognized that daycare was a reality for many families, Patricia also noted that children who attended daycare got sick more often than children who did not attend, and may have had more episodes of otitis media. The last suggestion that Patricia gave parents was to access the health unit’s speech and language
clinic if they suspected their children might have a speech problem. Even if after the screening, the SLP felt that everything was fine; the children would then be “on the radar” and would be re-screened at six months intervals.

**Ways to Improve the System**

When discussing ways to improve the system, Patricia recognized that she was bound by the rules of the referral process, even if she recognized that it was a flawed system. One of her main concerns was the length of wait time. While everyone had to wait, she felt that a wait time of 3 to 4 months in an adult’s life was much different than in a child’s life, and that children should not have to wait as long. “In a perfect world, I wish there was a way to fast track them.” One suggestion she had was to hold otitis media clinics just for children twice a month. She was concerned about the delay in treatment “having a significant effect on their speech and language, their behaviour and educational progress.” She worried that sometimes the children who needed help “slip through the cracks if the referral process doesn’t work and they don’t get treatment in a timely fashion.”

**Summary of Patricia’s Interview**

The thread that ran through Patricia’s interview was her desire to expedite the process to help children receive the treatment they needed. She believed that the current wait times of 4 months to see an ENT was too long for young children and she tried to triage some of the more urgent cases through audiology. She also believed in educating parents so they could better understand the struggles their children were having. She
urged parents to understand what treatments their children needed and to make sure they were receiving them.

Sharon (SLP): “Our Toes aren’t in with the Educational [System], and We’re Definitely not a Medical Model”

Sharon’s Background

Sharon, was a speech and language pathologist (SLP) with 10 years experience working with children, had a bachelor’s degree in education, and a master’s degree in speech and language pathology. She currently worked for a health unit agency that provided therapy to preschool children from birth until they entered Senior Kindergarten. Within the agency Sharon worked with two sets of clients. The first population she worked with was children with a range of communication difficulties, including speech and language and social communication. The second population she worked with was children who had permanent hearing loss, and she handled issues like cochlear implants and hearing aids. Sharon discussed TCHL for both populations of children. While the aim of this research did not address conductive hearing loss in children with a permanent hearing loss, Sharon explained that TCHL could occur in both populations, and create further challenges for children who already had hearing problems.

During Sharon’s interview five themes were evident: strategies used to help children; communication between professionals; communication with parents; advice to parents; and ways to improve the system.
Strategies Used

Sharon was well aware that the literature in TCHL was inconclusive, but expressed that she felt it was important to treat the existing issues that the children coming through her program exhibited. Sharon felt that it was “just common sense that having some fluctuating or intermittent hearing loss would influence speech or language and reading issues.” She went on to say that “just because we don’t definitely know what the long term causal influences are doesn’t mean we can’t still help a child in the here and now with what they’re going through.” One of the frustrations Sharon explained was that TCHL was “a floating target,” because the hearing changed with the amount of fluid in the ear, and this made it hard for the child to hear what different speech signals sounded like.

When children went into the speech and language program they were assessed by a SLP, and a wide range of interventions could be recommended. Sharon explained that group sessions were often used for children with similar issues. After a few group sessions, the child went back to the SLP for a few one-on-one sessions, followed again by a group session. After 8 to 12 weeks the children took a short break to assimilate the new information they had learned, and then returned to the program to be reassessed and begin more sessions if needed.

In the group and one-on-one sessions Sharon worked with the children and parents to share strategies. While Sharon explained these strategies would work well with all children, parents with children with hearing problems, such as TCHL, need to be more intentional in using the strategies. The strategies Sharon uses were:
…waiting for the child to take the lead, waiting for them to initiate, so giving
them that extra chance to process the information. Be face-to-face, and down on
the floor with the child so they can see your face and model and
interact….imitating back what the child says so they can hear you model,
expanding on the language like adding a word so they can build on what you said,
and waiting for them to try to imitate.

When we discussed the various types of group sessions that Sharon’s program offered
she reported that the programs focused on “phonological awareness skills, their
[children’s] listening, their rhyming, their segmenting words, and all those pre-reading
skills, and having them recognize their name.”

Sharon reported that she took the strategies one step further and suggested that in
the classroom the teachers should be intentional in the strategies they used for children
with TCHL. She suggested that teachers needed to think about where the children were
sitting, whether they are in a good location to see and hear the teacher, with the least
amount of background noise to distract them. She also suggested that the teacher should
model to help develop the children’s speech.

One informative aspect of the interview emerged when Sharon stated that
“children are coming here for a range of reasons and they may or may not have hearing
loss.” In our discussion Sharon explained that the program did not track children with
TCHL as closely as it tracked children with a permanent hearing loss, so it was not
always obvious when children had speech and language problems that were due to
TCHL.
Communication between Professionals

The relationship between Sharon and both medical and educational professionals was discussed during the interview. Sharon explained that the role of the SLP was interesting because it did not fit within either the medical or educational system:

…in some ways we’re our own entity, because our toes aren’t in with the educational [system], and we’re definitely not a medical model, so we’re more community based and we’re more like the educational model….I would say definitely, definitely not the medical model, very different.”

In referring to the medical professionals Sharon commented that, while her program strongly encouraged parents to take their children to their family doctor and ENT for check-ups and hearing tests, she was not aware of whether the doctors suggested that parents brought their children to the speech and language program. Because the speech and language program was a self-referral program the parents could request appointments.

One of the frustrations that Sharon mentioned a number of times during the interview was the “barriers to referral” when discussing her relationship with medical professionals. The three most common professionals that Sharon communicated with were the family doctor, the ENT, and the audiologist. In her initial assessment of children Sharon asked if the children had had a hearing test, to rule out hearing loss. If the children had not had one, Sharon, with the parent’s permission, sent a note to the family doctor requesting one. Sharon could not directly ask the ENT or audiologist for a hearing test because this referral could only be initiated by a doctor. The parents then would go to
the family doctor to request a hearing test, the family doctor sent a referral to the ENT or audiologist, and they in turn sent the results back to the family doctor. Sharon was clear to point out that nowhere in the process did the results from the hearing test come directly to her, even though she may have been the person who initially requested the test:

Getting information through the doctors is not always the easiest for us. Because we’re not physicians we don’t often get cc’d information back…We would send a letter to the family doctor [requesting the referral], but because the family doctor is the referring service, the information goes back to him or her and doesn’t come back to us.

Sharon then had to take the time to track down the report, whether it was sending a written request to the family doctor, or to the ENT to ask for the results. Sharon felt that it was a cumbersome system. The mode of communication between Sharon and the medical professionals was either indirectly through the parents or in written form. Face-to-face or phone conversations were not the typical way, “[it’s] just the way the medical model is, it’s just not to have a conversation with someone like an ENT, it’s very, very, very hard.”

The speech and language program where Sharon worked was set up to work with children until they enter Senior Kindergarten, at which time the school system was responsible for speech and language therapy. Sharon acknowledged that it was a “complicated system,” because while the program was funded through the Ministry of Health, children who had been in school for Junior Kindergarten still attended the program. When the children entered into Senior Kindergarten, Sharon, with the parents’ permission, sent the school a “transition to school report” which summarized the therapy.
She believed that this report was given to the SST, whom she assumed shared it with the school SLP and the classroom teacher. Sharon acknowledged that she did not have contact with the school SLP because their jobs did not overlap.

While Sharon expressed difficulty communicating directly with medical professionals, she did not have the same difficulty with education professionals. She reported that while she primarily communicated with teachers via reports and letters, she had found it easy to phone them or exchange emails when needed. Although phone calls during the day could be difficult to coordinate with a teacher’s schedule, she still found it easier than with the medical professionals, “I would phone a teacher, I definitely wouldn’t hesitate to give a teacher a call about something.”

Sharon did not often do on-site visits to schools, but had when the need had arisen. When she had gone into the school it was always for the children in Junior Kindergarten, and was usually for children who had to deal with multiple learning challenges. When she did go on-site it was usually to give a teacher suggestions or for an observation to get some information from the teacher, “a little bit of back and forth.” Sharon felt comfortable communicating in a face-to-face collaborative manner, she said because in her program the SLPs collaborated with each other to work through possible strategies to improve their services.

**Communication between Professional and Parents**

The relationship between the SLP and the parents was an important one in Sharon’s opinion, because the SLP needs to rely quite a bit on the parents for information. Because obtaining medical information directly from the doctors was
difficult, Sharon often relied on the parents to fill in the gaps. She asked the parents for the family history, including the children’s hearing history and ear infections. One aspect that was difficult was to know if the medical information the parents were passing on was correct. “They are passing some information along to me verbally, which in fairness to them, may or may not be accurate. It’s hard to capture, so sometimes it’ll be a bit misleading.”

One main difference in how Sharon saw her interaction with the parents compared to the medical or education professionals, was that she saw the parents as her clients as much as the children:

They [parents] are very involved, they are always in the sessions here with us, [and] so we have that advantage of that relationship to really promote. The parent is the primary facilitator in language. You’re the one that needs to do this at home. It’s like practicing the piano, you can’t just come for lessons, you have to do your work during the week then come back to class, [to see] what’s the next step and where we are going from here.

In her opinion this relationship was much different from the medical professionals’ whose focus was the children who were presenting the issues, and differed from the educational professionals who interact with big groups of children at the same time without the parents present.

**Advice to Parents**

Sharon advised parents who had children with TCHL to know what their options were, to visit their family doctor, and to know “how it’s [TCHL] is being managed, or
what the plan is.” She encouraged parents to learn the strategies that she taught and to be aware of the “acoustic environment. Turning off the TV and minimizing the background noises… [having] their attention before giving messages, making sure they understand the messages.” And most importantly “try to watch them and see how much they are impacted by this.”

**Ways to Improve the System**

Sharon was clear about improvements that she believed would improve the system. When discussing the medical system, Sharon said she would like the SLPs to be included “in the loop with the physicians.” This would mean being included in all of the reports as a matter of course. In dealing with the educational system, Sharon said she would like to see more feedback coming from the schools. She sent the transition to school report, but did not receive feedback about it. She reported wanting to know if the school had received all the information they required. “We rarely hear anything when we send the information there.” Ideally she would have liked to see more back and forth interaction with the classroom teacher during the Junior Kindergarten year, not just for the children with multiple disabilities. Although Sharon was happy with the overall communication between herself and the teachers, she still felt it was challenging to get information back from the teachers. “In that sort of set up it would have to come in the [children’s] backpack, to mum, and then back to us.”

**Summary of Sharon’s Interview**

The prevailing message in Sharon’s interview was that all professionals need to work together and with the parents to help the children succeed. Sharon believed that all
the professionals had a purpose in helping children with TCHL and with hearing issues, and that by working together they could create a seamless, barrier free, system for the children to thrive in. Sharon’s main concern was that communication between professionals was a barrier to the system working better, and only when everyone was included in the communication loop would a more seamless and effective system be achieved.

Olivia (student support teacher): “We Count on Our Partnerships with Other Professionals”

Olivia’s Background

Olivia was a student support teacher (SST) with 16 years experience teaching. She was a classroom teacher for 15 years, and has been a SST for the past year. The education involved to become a SST after obtaining a bachelor of education was Special Education Part 1 (a four month training offered as an additional qualifications course by the Ontario College of Teachers), and a six week course offered by the school board.

During the interview with Olivia, five themes emerged: the role of the SST, communication between professionals, communication with parents, advice to parents, and ways to improving the system.

The Role of the SST

Olivia saw her job as SST being divided into two roles: working with the children, and being the liaison between the school staff, other professionals, and parents. When she worked with children she withdrew small groups of students to work on specific strategies, or went into the classroom to co-teach with the classroom teacher. She
worked with children who had a variety of difficulties and disabilities from severe through mild disabilities to gifted students. Some of the students she worked with had reading difficulties, but not all:

Many children in the primary division have had difficulty with reading and it’s interesting that when we dig a little deeper [to] find that there’s been some hearing loss or there’s been a connection with ear infections and tubes and what not put in their ears and then [have] gone for a hearing test, to find out there’s been some hearing loss there.

In her role as the SST, Olivia helped to create an individual education plan (IEP) for children who needed the curriculum to be modified or for the student to be accommodated. In a team meeting of the classroom teacher, school administrator, SST and parents, the children’s strengths and weaknesses were considered and an IEP put together including strategies to help the children succeed in reading. Sometimes the IEP recommended withdrawing the children from class to a small group, or modifying the classroom curriculum to better suit the children.

In her role as liaison, she saw herself as “the pivotal person,” and reported that in her role she was the person who met with all of the professionals from the school board and professionals outside the school system, and conveyed information to the classroom teacher:

They [the SSTs] are the go-between and it helps to have somebody take in all the information and then be able to share it with the teacher at a more appropriate time because these professionals kind of fly in and they fly out and [the teacher
“they leave us some scripted note and it’s very difficult to understand what exactly they meant, and I really want to talk to them, but it’s hard to cause I have to teach my math lesson now and I can’t leave.”

Sometimes these meetings included Olivia conferencing with the families and professionals to understand the children’s needs and how they can best help them.

Olivia described some of the challenges of the job. She explained that the board she worked for often combined the role of the SST with the vice-principal role, allocating .75 of the day as SST time, and .25 of the day for vice-principal duties. It was unusual to find a full-time SST who did not have to split their day between roles in her school district. She cautioned however, that the administrative position could easily take much of the time, leaving less than there should be for SST duties. While at Olivia’s school there is no vice-principal role (as the school is too small), she does have to use the .25 administration time to cover classroom teachers’ planning time. The other aspect of the SST role that Olivia addressed was how often the SSTs were moved from school to school, and reported that in her school board sometimes people use the SST position as a stepping stone to becoming a vice-principal and do not stay in the position for long before becoming a principal. She commented that this led to a high turnover, and a steep learning curve each September as the SST tried to understand their new school and students, which used up valuable time.
Communicating with Professionals

While Olivia met with various professions from within and outside the school board, when dealing with children who had TCHL, she was most often in contact with the SLP and psycho-educational clinicians from within the school board:

We count on our partnerships with other out of school professionals, whether it’s a SLP, or anybody from any of the hospitals to come in and assist us in any way that we can draw on their expertise and programming.

When meeting with the other educational professionals Olivia expressed that “as part of our collaboration there [is] always a big meeting where we invite all the professionals including the parents…we figure out what other programs we could try with the students.” This form of communication was helpful to Olivia because it was face-to-face, which was something she valued.

One of the difficulties with the two school board professionals that Olivia worked with to help children who had TCHL was that:

we have very few [SLPs and psycho educational clinicians] that are spread across our entire board. So we will have a team meeting and decide who are our top players here that we really need to get going…and we’ll pick our top three students out of the whole school…who we think it’s critical right now for them to go, and that’s hard to do.

With so few of these professionals, SLPs and psycho-educational clinicians, many students were not being seen in a timely manner.
Olivia did not interact with the health unit SLPs, but commented that she received an assessment from the program when the children were finishing Junior Kindergarten to inform her about what the students had been working on up to that point, when they were discharged from their pre-school program. She did not spend much time discussing interactions with medical professionals, except to say that she had worked with some for students with severe disabilities, but that it was not a regular occurrence. She did not recall communicating with any medical professionals about children with TCHL.

**Communicating with the Parents**

Olivia stated that she valued parents as partners in helping their children be successful in school. She understood that:

parents play a very big role because sometimes they [the children] do different things for parents than they do for the teachers, which it’s nice to get their take on him. “You know he can do this at home,” or “I’ve never seen him do that, how come he’s doing that at school?” So, it’s nice to get their take on what they see and [to share] strategies that I’m doing in the classroom for them to do at home and vice versa.

Olivia knew that parents were concerned and wanted to get the best education for their children, so having them as part of the team that made the decisions about what services the children were going to receive made sense to her. Typically communication with parents happened face-to-face. This happened formally in a meeting to discuss the need for an assessment, the results of an assessment, or the initiation and up-dating of an IEP.
It also happened informally when parents dropped by Olivia’s office before and after school with a question or comment about their children.

While Olivia stated that she did not usually interact with medical professionals to help a child with TCHL, she reported asking the parents to visit their family doctor for a referral to a pediatrician or ENT to get tests done that she thought might be helpful in illuminating some problems. One of the first questions Olivia asked parents when children were brought to her attention because of a reading difficulty was whether there had been a medical referral put in to have their eyes tested, and to have their ears tested. If not, Olivia requested that the parents have these tests completed. Olivia had noticed that it was not uncommon for parents to ask how to go about getting these tests done. Olivia reported that she was quick to tell the parents exactly how to get the test done.

Advice to Parents

Olivia stated that she “doesn’t think many parents understand that hearing is really important,” and this concerned her. She was a strong believer in making the most of the early years with children:

the amount of lap time they’ve had with you with a book, all that early years
learning that you’ve heard them talk about, you’re talking with your child is really important to their development when they come to school in Kindergarten and throughout school.

While this was important for all children, Olivia noted that it was extremely important for children who have had hearing loss. She suggested to parents that if their children had been diagnosed with TCHL, then there might have been recommendations made. If there
had been recommendations, Olivia urged parents to bring these to the attention of the classroom teacher and the SST. She also suggested to parents that they “need to advocate for your child [ren] to say this is what I’ve discovered and how can we work together to make this work, or find a solution to make the learning continue.” In addition, Olivia believed having children tested for physical issues such as eye sight and hearing was a critical aspect of understanding their challenges.

Ways to Improve the System

Olivia had a few suggestions that she felt might help improve how children who have had TCHL or a reading difficulty were identified, assessed, and supported. All of the improvements she suggested were for procedures within the school. One of the first things Olivia suggested was for more training for primary teachers to help them understand the signs to look for in children having difficulty reading. She understood that each teacher had their own way of doing things, but the signs of a reading difficulty or a hearing difficulty were not always obvious.

Background noise was an issue for Olivia, and she was a strong advocate for anything that helped reduce background noise, allowing the children to focus more on what they were learning. One of the approaches that she knew helped to cut down background noise was the use of FM systems in classrooms. In an ideal world she would have liked to see the systems put in every classroom regardless of children’s hearing ability, “FM systems are good for everybody, it’s good for all, so I think that would be a plus.” In addition, some classrooms had hush-ups on the chairs to cut down on noise. These are inflated tennis balls that fit on the bottom of chair legs to reduce the noise when a chair moves across the floor. She would have liked to see these more widely used,
and see people conscious of being quiet while walking down the hallway in respect for other learners.

Another suggestion Olivia gave to improve the system was the use of hearing tests within the school:

…we have vision tests for students at particular times through the year, [and] the board does it. We have dental checks come in right from Kindergarten, then Grade 2, then Grade 4. Why don’t they have someone come in and test their hearing?”

Having hearing tests in school for all students would help identify students with hearing difficulties that might otherwise be missed.

The last suggestion Olivia gave to improve the system was directed at her position as a SST. She wished for more time to do her job more thoroughly, this included more time to talk with classroom teachers, other professionals, parents, and students. She felt stretched as a SST to try to help all of the students and reported that there was not enough time to help everyone as much as they might have needed. She suggested having SSTs move around so often from school to school was not a good use of resources. Having a SST remain in a school longer would allow for better service because the SST did not have to spend time learning who everyone was, and what their needs were, “coming back [to the same school] in September, I would be that much further ahead.”
Summary of Olivia’s Interview

In summary, Olivia’s interview was focused on two aspects: her role with children and her role with other professionals and parents. Ultimately, the goal for both of these roles was the success of the children. Olivia believed that her role as the SST was pivotal in creating partnerships between the school and any outside professionals, and that it was her job to help develop the best possible plan to utilize available personnel and resources to help the students in her school to be as successful as possible.

Frances (Classroom Teacher): “I Want My Children to be Successful”

Background

Frances was a primary classroom teacher with 23 years experience who was currently teaching a Grade 1/2 split. She had earned a bachelor’s degree and a master’s degree in music and then a bachelor’s degree in education. Frances felt that her training in music had helped her teach language and reading because “I hear things very keenly. I hear sounds and how sounds are produced… I think it supports reading.” Frances reported that she did not feel she had much experience working with children with TCHL. This was not information parents typically shared with her and was not something she could identify from the children’s activities in the classroom. She reported being knowledgeable about how children learn to read. Frances was included in this study not because she had any special background with children with TCHL. She heard about the study and volunteered. During the interview Frances claimed to have little experience with, and little knowledge about children with hearing loss. She was willing to share her perspective as a primary teacher in the school system, and spoke mainly about helping
children learn to read and about her communication with other adults about children’s reading. When asked how her teacher education prepared her to help identify and teach children with reading difficulties, Frances replied “very, very little. Negligible.” She expresses that she was never “trained” in her job adequately, but what she had learned about reading had come from self-study, problem solving, and talking to her colleagues.

In the interview with Frances five themes emerged: strategies for teaching children to read; communicating with professionals; communicating with parents; advice to parents; and ways to improve the system.

**Teaching Strategies**

Without knowledge about specifically teaching children with TCHL to read, Frances described teaching strategies that she used with all of her students. Her emphasis was on children who were struggling to read, no matter what their reason. She reported that often she did not know why individual children were struggling. There were three main strategies for learning to read that Frances discussed: the use of sight words, reading at the children’s level, and working on word families. Frances believed that all children needed a bank of sight works so she used the Dolce list of sight words. She used them in games, and in take home spelling words so the children had many opportunities to practice the words. The second strategy that Frances used was to find reading material that was at the level of the children:

finding reading material that is at the level that the child[ren] are working with is absolutely essential so that they experience success and make incremental growth so that there’s not too much in there that is going to prevent comprehension.
The last strategy she used was word families. Word families are groups of words that have a common pattern, in that they have some of the same combinations of letters in them and a similar sound. While using these strategies, Frances did not separate the children into “special tables,” but integrated them to work together as she “believes children learn as much from one another as they do from the teacher.”

Frances took a special interest in children who were having difficulty learning to read, whether or not she knew the difficulties arose from TCHL. She “nurture[s] the child [ren], building a good relationship and tries to find something to hook the kid[s] into wanting to learn.” Although building a relationship was important with all of her students, Frances noted that she took a special interest in the children who were struggling because she wanted all of her students to be successful.

**Communicating with Professionals**

Although Frances discussed her relationship with other professionals, she reported that the majority of people she interacted with were from within the educational system. Most of her professional interactions were with other teachers, either sharing resources, problem-solving difficult issues, or discussing student placements. The interaction was typically face-to-face, either in a formal meeting or in informal chats during the day.

Other professionals Frances reported interacting with were the SLP and SST. With the SLP she expressed that “they [the children] don’t get enough help, they only get a few sessions,” and Frances felt many children needed much more than was offered, not just the children with TCHL. She described that the SLP wrote a report and left it in the classroom, because Frances did not have time to talk to them during her teaching time.
She took the strategies the SLP had taught the children, and used them in the classroom with the individual children to further develop these skills. When speaking of the SST, she confided that she has never had much support. She was not sure why she had not received help from the SST, but suggested that perhaps “there are just so many needy children in the school [and] I’m not on the priority list.” She did, however, have one student who was withdrawn from class by the SST to work in a small group on reading skills.

About medical professionals, Frances expressed that she did not interact with many. She had the occasion to have an occupational therapist work with a few of her students, but felt that they had lower expectation of the students than what the students were capable of.

**Communicating with Parents**

Frances described how important the relationship she built with the parents of her students was to her:

I nurture the parents, I work with the parent ‘cause of course I want the kid to be successful….I want to be successful, I want to help that child [to] read so working with the parent is essential for the child’s success.

Although she valued this relationship, she reported that she normally had to be the one to approach the parent, not the other way around, “I make the contact and I encourage the growth. It’s my initiative; it has to be on my initiative.” Some of the ways Frances supported the parents of all of her students was by providing resources for them to work
on at home, including simple word games, flash cards, and a daily supply of books to read with the children.

Frances met with the parents to discuss the children’s progress, including areas of strengths and weaknesses. She also sent home notes to remind parents of some of the strategies the children needed to work on. This was in addition to regular report cards. She expressed concern that parents probably did not truly understand just how important hearing was to the learning process. When asked if parents often told her that their children have had ear infections, she said that they rarely shared that information.

**Advice to Parents**

One of the key pieces of advice Frances reported giving to parents of children with TCHL and children who had a reading difficulty was to “find a really good teacher….A good teacher is essential.” She emphasized a number of times in her interview the need for a good teacher who has the skills to help struggling readers. Frances also recommended spending considerable time reading with their children, after finding out what their children’s passions and interests were and finding appropriate books. She suggested that “it doesn’t matter if it’s comic books, [or] if it’s playing Lego and reading the directions together,” there has to be reading taking place. She believed love of reading leads to children reading more and, the more they practice the better they get. She encouraged parents to make it a positive experience for everyone. The last piece of advice Frances gave to parents was to find a specialized program if necessary. If their children’s needs were not being met in the classroom, she advised them to look beyond the classroom to get their children what they needed to succeed.
Way to Improve the System

Frances was concerned about the lack of education for teachers in the area of reading development. Reflecting on her own education at university and her work with teacher candidates, she expressed the opinion that reading was only skimmed over, and not taught in enough depth. While this level of teacher education might be adequate for teaching good readers, she thought children who struggled with reading need to:

work with people who know what they’re doing. They need to work with people who know how to teach reading and know how to work with language and to choose appropriate materials…It takes a trained person who really knows how to teach language and knows how to teach reading, to assess that and to be really effective.

Frances suggested that the average teacher had to take extra courses to better understand reading, but that many teachers did not do that. She expressed the view that for the system to improve, the education of teachers must improve.

Frances’ second recommendation was for more time. She realized that the lack of time was a reality of her job, but thought in an ideal world teachers would have more time to collaborate with parents of children who were struggling to read, and able to follow up more closely with the strategies she recommended to them.

Summary of Frances’ Interview

The prevailing message in the interview with Frances was that she was passionate about teaching all of her students to the best of her ability. She did not feel that she had much experience working with children with TCHL, as parents did not typically share
that information with her, but she did feel knowledgeable about how children learn to read. Frances expressed frustration a number of times at not feeling adequately supported by specialists whose jobs it was to help her teach her struggling readers. Lack of adequate teacher education for teaching struggling readers was also a thread throughout the interview. Frances believed that parents were an important partner in helping struggling readers, and that it was by teachers creating relationships with parents that the children could benefit most.

**Cross-Case Analysis**

Extensive analysis of each individual interview was conducted followed by a cross-case analysis. While each interview provided information of the participants own experiences, a cross-case analysis may help increase our understanding of the whole process experienced by children with TCHL, by viewing the process from different perspectives. The participants will be compared according to the major themes that emerged from analysis of the individual interviews.

**Knowledge Base of Each Participant**

The parents in this study were not trained to diagnose and treat otitis media and TCHL. However, their personal lived experiences taught them about otitis media and TCHL and about advocating for their children. The parents recognized that their job was not to understand all the nuances of otitis media, but to be the advocates who sought the specialists with the knowledge. Although neither parent was trained specifically in otitis media, Bethany had a nursing background and had a stronger understanding of the medical aspects of the disease than Sonia.
All the professionals, both medical and educational, were trained in their own fields, reaching various levels of specialization. While the professional education for the medical professionals included specific education in otitis media and TCHL, the education for the educational professionals did not. However, the educational professionals had varying degrees of education in reading development and the medical professionals did not. The SLP, who did not clearly fall into either the medical or educational professionals, expressed the widest knowledge about all three aspects under discussion: otitis media, TCHL, and reading development.

While discussing children with otitis media and TCHL, all the professionals regularly moved the discussion to children with other disabilities. This occurred 27 times during their interviews. For example, the SLP kept changing to discussing her role with the children with permanent hearing loss, the audiologist referred to strategies she used for children with permanent hearing loss, and the SST and classroom teacher referred to children with multiple learning disabilities. This suggested that all the professionals were better informed and more comfortable discussing other conditions than discussing TCHL.

**Communication between Professionals**

The communication styles were quite different among the professionals. While both the medical and educational professionals discussed the concept of working collaboratively with colleagues, the definition of collaborative work was quite different.

The medical professionals discussed collaboration in terms of written communication. When asked about collaboration, Dr. White, the family physician, replied “Collaborate? I think I always collaborate in that I work in a collaborative manner
with ENT and pediatrics.” And when asked when she worked directly with her medical colleagues she answered “never.” The form of collaboration Dr. White was discussing was the referral process. The family doctor sent written referrals to the ENT and the audiologist, and the ENT sent written referrals to the audiologist. After assessing or treating the children the referred professional then sent the physician a written report with the results. It was not common practice for the medical professionals to meet face-to-face because each met with the children for different specific purposes. While the medical professionals stated that this system of referrals and reports worked for the medical system, it was a very different idea of collaboration than the educational professionals described.

The educational professionals spoke of collaboration in terms of team meetings and face-to-face problem solving. The teacher and SST discussed working in direct physical contact with other professionals. This would often include a written report to document the results of an assessment or an individual education plan for the children, but the face-to-face meeting was the most prevalent. Olivia’s statement represented a common collaborative practice by educational professionals, “as part of our collaboration there was always a big meeting where we’d invite all the professionals…we’d figure out what other programs we could try with the students.” When a large meeting was unnecessary, informal face-to-face discussions between two educational staff members would take place.

The interaction between the medical professionals and educational professionals varied depending on whose perspective was being reported. Dr. White and Dr. Miles reported that they did not have regular contact with educational professionals. Dr. Miles
reported that it was rare, but, on occasion a school might request a copy of a hearing test. This request had always been in a written form, as was the reply. Patricia, the audiologist, reported having some interaction with educational professionals. It was usually in a face-to-face meeting to discuss hearing aids or sound field systems for children with severe hearing issues, not usually children with TCHL. The educational professionals reported having varied interaction levels with medical professionals. Olivia, the SST, reported having regular interactions with medical professionals, but it was not with the professionals that were being interviewed for this study, nor about children with otitis media and TCHL. The classroom teacher reported having little interaction with any non-educational professionals.

Sharon, the SLP, was an intriguing addition to this study because her position placed her between the medical and educational systems, interacting with both, but not feeling a part of either. In her interactions with the medical professionals, Sharon reported that her interactions took place in a written form. To receive any information from medical tests Sharon had to make the request in writing, and received a written report. She expressed that “getting information through the doctors is not always the easiest for us, because we’re not physicians.” Sharon expressed that she found it easier to communicate with educational professionals than medical staff. When Sharon interacted with educational professionals there was a written component, in the transition to school report, but there were also direct face-to-face interactions and, more frequently, phone conversations.

One consistent aspect of their roles that was mentioned by both medical and educational professionals was the shortage of time. Time was mentioned by the medical
professionals when discussing the long wait times before children could receive necessary tests and treatments. The educational professionals commented on the lack of time to do their job thoroughly.

When the parents were asked to comment about the interactions they had witnessed between the professionals, Sonia expressed that there was a lack of communication between the medical and educational systems. She felt that she had to be the intermediary between them, and it was up to her to remember all the details to pass to the next professional. Bethany reported that she had never seen any interaction between medical and educational professionals on behalf of her son, and that it was left to her to make sure every professional involved with her son knew the various aspects of his diagnosis.

**Communication between the Professionals and the Parents**

The medical professionals commented that one aspect of communicating with the parents was educating them about the particular aspect of otitis media and TCHL that was being discussed. For the two doctors this included informing about the options available for treatment, and why some treatments were recommended over others. Patricia, the audiologist, reported spending time educating the parents about what their children were able to hear.

The educational professionals discussed their communication with the parents as a partnership in which the parents needed to have a voice to help solve problems. Frances, the teacher, reported spending some time helping parents learn reading strategies so they could help their children at home. Sharon, the SLP, saw the parents as clients as much as
the children. While she taught strategies to the children, the parents were also there to learn them, so that the strategies could be reinforced at home. While Frances felt that communication between the classroom teacher and the parents was always initiated by her, the parent Bethany expressed that she was the one who had always had to initiate contact with her child’s classroom teachers. As this was a cross-case study Frances and Bethany were not talking about each other, but about their separate experiences.

Although Sonia was unhappy with her interactions with the medical professionals, and generally satisfied with her interactions with the educational staff, Bethany’s experience was quite the opposite. Sonia reported not feeling listened to by many of the medical staff. She discussed how after her son did not receive a full hearing test, she bypassed the ENT and asked her family doctor for a referral directly to the audiologist and named the test she wanted to have done. With the educational professionals, she still had to advocate for her son, but she felt that she was listened to and her concerns were taken seriously. Bethany reported that she felt the medical staff listened to her concerns and gave treatment that was somewhat based on her concerns. She expressed that this may have been because the staff knew about her background in nursing. Bethany also expressed feeling ignored by the educational professionals. She reported that classroom teachers and the SST consistently told her that there was nothing to be concerned about, and that her son’s reading difficulties were gender based and he would grow out of them. In both parents’ experiences they felt that their family doctors listened to their concerns and took them seriously.
Advice to Parents

All the professionals encouraged the parents to be strong advocates for their children. They all mentioned the need for parents to inform themselves, to ask questions of the professionals, and to be willing to speak up when they feel that their children’s needs were not being met. Although advocacy was the same advice the two parent participants offered, the parents’ experiences varied as to the support of the professionals.

Both parents put a strong emphasis on advocacy. Advocacy was a main thread that ran throughout both of their interviews. They strongly encouraged parents to take charge, to know what assessment and treatments their children might require, and to stay on top of the issues to ensure the professionals were doing what they said they were going to do. Both parents urged other parents not to be swayed by professionals minimizing their concerns, but to trust themselves if they felt that something was not right. About the medical professionals, both parents suggested using the family doctor as an ally and working around other medical professionals if they were not getting what they needed. With the educational professionals, both parents suggested being present in the school as often as possible, to meet with the classroom teachers to make sure both teachers and parents know what is happening with their children, and to be part of the team that creates the plan of action. In addition, the parents recommended moving outside of the system to pay for private services, when possible, if services are not being made available within the school system. This was an important issue for both parents, and they were very strong in their recommendation for other parents to stand up for their children.
Ways to Improve the System

All of the medical professionals suggested that one of the best ways to improve the system would be to reduce wait times for ENT and audiology appointments. There was a definite concern that children needed to be seen sooner to minimize any potential problems that could arise from extended periods of otitis media including TCHL.

Patricia, the audiologist was concerned that the delay in treatment due to long wait times could “have a significant effect on their [children’s] speech and language, their behaviour, and educational progress.” Dr. Miles, the ENT, was also concerned that he was unable to create more time to see additional children and it was due to a lack of clinic space and equipment.

One of the suggestions that both Olivia (SST) and Frances (classroom teacher) felt was important was the need for better education for teachers. Frances commented that “It takes a trained person who really knows how to teach language and knows how to teach reading, to assess that and to be really effective.” There was concern by both professionals that education for teachers and SSTs was limited and needed to be more thorough.

It was informative to note that it was only Sharon, the SLP, who made recommendations to both the medical and educational systems. The other professionals tended to make recommendations only within their system. Sharon recommended better communication between all professionals. With the medical professionals she saw a need for more than just the physicians to be included in results from tests. In her view, all professionals dealing with the children’s cases needed to be informed of what diagnosis and treatments were happening. When discussing the educational system, Sharon saw the
need for more communication there too. While she expressed more satisfaction with her communication with the educational professionals than the medical professionals, she still thought there was a gap in feedback after the transition to school report had been sent out.

**Distinguishing Issues**

Cross-case analysis did not identify any further common themes; however it did identify one additional theme present in three of the interviews: Dr. Miles (ENT), Sharon (SLP), and Olivia (SST). In addition, there was one different theme that arose in both of the parents’ interviews and did not arise in the interviews with any of the professionals.

Although each of the professionals discussed their role in the process of diagnosing and treating children with otitis media, three of the professionals went into greater detail than the remaining three. As an ENT who specialized in otitis media in children, Dr. Miles’ had much to contribute to the discussion. His description of the range of children he saw, what the physical symptoms were, and how he treated otitis media showed how strong his knowledge was on the subject. Sharon, the SLP, spent considerable time discussing strategies she used with children who had speech difficulties, more time than the other professionals. The last professional who went into greater detail about her job with children with TCHL was Olivia, the SST. As Olivia’s job had two distinct aspects to it she was detailed about her role.

Slightly different themes emerged from the two parents’ interviews than from the interviews with all the professionals. This was not unexpected as their point of view was quite different from the professionals. While the communication between professionals
and parents was one theme for the professionals, it became two themes for the parents: communication between medical professionals and parents, and communication between educational professionals and parents. This difference occurred because while each of the professionals could only comment on the communication between themselves and the parents, the parents could comment on the communication they had had with all of the professionals. While each of the professionals expressed satisfaction with how they interacted with the parents, this was not the case from the parents’ perspective. As previously discussed each parent had good communication where they felt heard and poor communication where they felt ignored and belittled. The other theme that emerged from the parents’ interviews was advocacy. While each of the professionals mentioned parent advocacy, it was the parents who expressed advocacy as an over-riding theme throughout their interview.

Thorough examination of each interview and a cross-case analysis has provided a richer understanding of the lived experience of the eight participants by comparing similarities and differences. The participants were not discussing the same case, and this allowed for them to discuss their experiences in a more extensive and wide range manner that was more applicable to more children. The next chapter addresses the five research questions asked in chapter one, relates the findings of this thesis to previous literature, and makes recommendations for future research and for practice.
Chapter 5: Discussion

The purpose of this study was to provide detailed descriptions of how medical and educational professionals report they communicate with parents about the potential reading risks associated with TCHL. In addition, the study was to provide descriptions of how parents advocated for their children’s needs in the medical and educational systems. It is important to remember that the participants were not discussing the same case, but drew on their extensive, wide range of experiences that are applicable to more children that the discussion of one case would allow.

This study aimed to answer the question: from the perspectives of professionals and parents, how do the medical and educational professionals communicate with parents about the potential complications hearing loss can have on reading development? In addressing this question four sub-questions were also addressed: (a) What awareness do medical and educational practitioners report about the connection between hearing loss and reading development? (b) What specific knowledge do medical and educational professionals think parents need to know about the relationship of TCHL to reading development? (c) What specific knowledge do parents report they need to know about the relationship of temporary conductive hearing loss to reading development? And (d) From the perspective of the professionals and the parents, what are the roles and responsibilities of each professional in supporting and educating children with hearing loss?

This chapter discusses the researcher’s interpretation of the findings in addressing the research questions and addresses the limitations of the research design for answering these questions. The relationship between this study’s findings and the current literature
is considered, and finally recommendations are discussed in two areas: future research and future practice.

The parents and professionals were chosen as participants for this study based on their personal or professional connection to the process children with TCHL due to otitis media might go through. The data showed that the participants had a number of experiences in common, but that these experiences were viewed from their own unique perspectives. The next section discusses how these findings answer the five research questions.

**Professional Knowledge of Hearing Loss and Reading Development**

The first research question focused on the knowledge base of the medical and educational professionals in the areas of TCHL and reading development. All of the professionals expressed knowledge of either TCHL or reading development, not usually of both. The medical professionals discussed their knowledge of TCHL due to otitis media, and the educational professionals discussed their knowledge of reading development, it was only the SLP, who fit in neither the medical or in the educational system, who expressed much knowledge of both parts of the process. Dr. White, the family doctor, reported that she discussed reading development with the parents of children who were struggling, but not in great detail because in her view this was the domain of the education system. Dr. Miles (ENT) and Patricia (audiologist) were clear that they did not have any knowledge of reading development.

The educational professionals, both Olivia (SST) and Frances (teacher), stated that while they did not have a great deal of knowledge about TCHL, they felt knowledgeable about reading development. Sharon (SLP) was the only professional who
expressed some knowledge of both TCHL and pre-reading development. She explained that while she focused primarily on speech development, TCHL is one aspect that could hinder speech development. She also facilitated groups for children that focused on phonological awareness and pre-reading skills. She did not however focus on later reading skills. While the professionals usually had knowledge of TCHL or reading development, it was primarily the SST and the SLP that expressed an understanding that there may be a connection between the two. Sharon, the SLP, held the view that it was “just common sense” that TCHL would influence reading development. Olivia (SST) expressed that after children were referred to her for reading difficulties, she was not surprised when she was informed there had been previous hearing issues.

**What Professionals Think Parents Need to Know**

The second research question focused on what knowledge the professionals thought parents of children with TCHL needed to know about TCHL and reading development. Once again, the medical professionals focused on what knowledge the parents needed to know about TCHL, and the educational professionals focused on the knowledge they believed parents needed to know about reading.

The medical professionals discussed that parents needed to be educated about the options available to children with otitis media and TCHL. Dr. White and Dr. Miles expressed concern that parents did not always know the consequences of different options, such as antibiotics and insertion of tubes. The doctors reported that they felt parents did not know that antibiotics are only appropriate in some cases, and that tubes are often a good solution even though the surgery intimidates some parents. Patricia (the audiologist) reported that parents needed to have a better understanding of what their
children are actually able to hear. She felt that by parents having a better understanding of what their children are actually hearing, they could be more realistic in their expectations of their children.

The educational professionals discussed the need for parents to know a variety of reading strategies to support their children’s reading development at home. Frances (the teacher) reported that parents needed to read continuously with their children. She discussed various strategies to help parents support their children in the reading process in an effort to teach their children to love reading. Olivia (SST) also expressed the need for parents to help their children develop a love of reading. She felt that parents need a better understanding of how important hearing is to the development of reading, and thought that, when there are any difficulties in reading development, parents need to know to have their children’s hearing and vision tested.

Sharon, the SLP, reported concerns about parents similar to those expressed by the medical professionals regarding TCHL, but also went into educational concerns regarding learning development. Sharon expressed a need for parents to know what their options are if their children have TCHL, to ask medical professionals questions and to know about the plan for treatment. She also felt that parents needed to be aware of the impact that background noises in the home were having on their children with TCHL.

What Parents Need to Know

The third research question asked about what knowledge the parents thought other parents needed to know about a potential relationship between TCHL and reading development. One of the main concerns the two parents expressed, that they wanted other
Parents to know, was the need to be an advocate for your children. Both parents felt that without their contribution their children would not have received the assessments and treatments that they had. Both Sonia and Bethany reported that parents need to pay attention to what is happening with their children, and to monitor whether what the professionals are saying is congruent what the parents are seeing. If the parents think there is a difference, they need to advocate for their children in any way they feel necessary, whether this involves bypassing a professional or openly disagreeing with an assessment.

In addition, both parents expressed the need for parents to be honest with themselves. They felt that, as parents, it is important to know what their children’s strengths and weaknesses are, and not to deny a problem if they see it. Sonia expressed that the parents are not helping their children if they pretend that their children are fine when they are not.

**Professional Role and Responsibilities**

The fourth research question asked what the roles and responsibilities were of each of the professionals in supporting and educating children with TCHL. The majority of professionals reported that their roles and responsibilities were specific to one area. The medical professionals reported being responsible for diagnosing and treating otitis media and TCHL. Dr. White reported that her role as a family doctor was to be the initial diagnostician and that it was her role to decide on a course of treatment for TCHL, and on whether a referral to additional treatment was necessary. Dr. Miles expressed that his role as an ENT was to diagnose the extent of problems occurring because of otitis media and to recommend a course of treatment. Patricia (the audiologist) described her
responsibilities as focused on testing for a hearing loss. Although educating the parents about the medical options available to treat otitis media was an aspect of their role, they reported that informing the parents about potential reading difficulties was not part of their responsibilities.

The educational professionals expressed that their roles were in educating children with TCHL. While both the SST and classroom teacher expressed that they were not specifically trained in TCHL, they knew how to teach children who were having difficulties in reading. Frances, the classroom teacher, reported that her role was to facilitate student success in all aspects of their education, including reading. She used various reading strategies to help her students, and referred to other professionals for support solving problems as they arose. Olivia reported that her role as a SST was to support students by bringing in various professionals as needed. She was also responsible for helping to create individual education plans, and for working with children one-on-one or in small groups to support reading development.

Sharon reported her role as a SLP was to help children with speech and language problems. These problems may or may not have occurred because of TCHL. She viewed her role as falling between the medical and educational systems, not fitting clearly in one or the other. She reported that she referred children that she suspected of have hearing problems to their doctor for diagnosis and treatment, and she sent reports of what she had worked on with the children to the educational system, but she was responsible for only the speech aspect of the process. There was no professional whose roles and responsibilities included knowing all aspects of TCHL and reading development.
How Professionals Communicate with Parents

The four preceding research questions help to answer the overriding question of this research: from the perspectives of professionals and parents, how do the medical and educational professionals communicate with parents about the potential complications hearing loss can have on reading development?

The two parents who participated in this research expressed that there was very little communication from any of the professionals regarding potential complications TCHL could have on reading development. Bethany reported that even with her background as a nurse she did not appreciate the potential repercussions of TCHL. Both parents reported that they did not recall being told by any of the professionals that there might be an impact from TCHL on their children’s reading development. It was not until both children were in school and started having problems with reading that the parents started questioning the professionals about potential reasons for the problems, and then hearing loss was raised.

Each of the professionals expressed that they viewed communicating with the parents as part of their jobs. However, the professionals reported that they communicated the aspects of TCHL and reading development that they felt knowledgeable about. This meant that the medical professionals communicated potential hearing loss, the educational professionals communicated about problems they saw related to reading development, and the SLP discussed concerns about speech and language. No one professional reported that they communicated with parents about the potential ramifications that TCHL could have on reading development.
Study and the Literature

The results of this study are compared to the research in the literature review, and there are similar findings. Both of the doctors and the audiologist in this study expressed the view that otitis media is the most common reason for young children to go to the doctor (Casby, 2001), and is most prevalent in preschool age children (Daly, Hunter, Levine, Lindgren & Giebink, 1998), and that it can be associated with a temporary hearing loss of mild to moderate (up to 55 decibels) intensity. As in the previous research, the professionals were not certain about a connection between TCHL and reading development. They did not give a clear answer as to whether there was a connection or not, they would only go as far as saying there may be a connection. While the medical professionals in this study made the connection between hearing loss and speech problems, they did not go further. The SLP made the connection from hearing loss to speech problems, and then went as far as suggesting a connection to possible phonological awareness problems. The educational professionals stated that they often saw children with reading difficulties before there had been any mention of previous TCHL, so were not certain of the connection. The statement that the SLP made seemed to put into words what many of the professionals expressed “just because we don’t definitely know what the long term causal influences are doesn’t mean we can’t still help a child in the here and now with what they’re going through.”

The professionals in this study identified similar findings as the literature for professional communication. The literature suggested that there were barriers to collaborative work between medical and educational professionals due to the systems having different organizational cultures (Law et al., 2001). The professionals who
participated in this study implied similar opinions as they had different forms of communicating, different ways of interacting with the children they saw, and different ideas about the role of the parents. The medical professionals communicated primarily through written referrals and reports, while education professionals primarily communicated face-to-face. The medical professionals saw the children on an as-needed basis, one-on-one, and worked with the children from their areas of deficit. The educational professionals saw the children daily, in group settings, and worked with the children from their areas of strengths. These differences created two distinct cultures.

The need for continuing professional development about meeting the needs of children with TCHL has been acknowledged in the literature (Law et al., 2001; Sadler, 2005), and was recognized by the study participants. Frances reported concern about the lack of teacher education for teaching reading development, especially for teaching children with reading difficulties, at the time of her teacher education. Dr. Miles also stated that he felt some physicians needed more professional education to keep up-to-date with the use of different treatments for otitis media, such as antibiotics.

The role of the parents was evident in the literature and in the interviews with the participants in this study. Both parent participants emphasized parent advocacy as they often felt they were ignored or belittled when voicing an opinion to the professionals. This is similar to the literature that found parents did not feel listened to by the professionals, and had to fight for whatever they felt their children needed (Lindsay & Dockrell, 2004).
As the literature suggested, early intervention for reading difficulties could be compromised if parents do not tell teachers that their children had TCHL, and the teacher does not know the potential root cause when a reading problem develops. Similarly, Frances (the teacher) implied that she did not know if many of her students had TCHL, but that she suggested that perhaps the parents just did not think to tell her. However, both Sonia and Bethany reported telling the teachers that their children had TCHL, but felt that some of the teachers did not appreciate the potential reading implications of TCHL.

**Limitations**

This research study was designed to better understand the different perspectives of the participants involved however there were some possible limitations. The first potential limitation was that the research was conducted with all participants talking about their experiences generally. This created some potential confusion as the participants were not discussing interacting with the same people. An example of this was when the parents and classroom teacher talked about the SLP they were referring to a school SLP; not a health unit SLP like the one who participated in this study. Although using one case study would have provided continuity with all participants discussing the same problems, the current design allowed for a wider range of experiences to be discussed and the concerns raised by the professionals were applicable to more children.

Another potential limitation of this study was that the researcher was a parent, a former teacher, and a novice researcher. Because of the possibility of introducing bias into the study, as a parent of children who had experienced TCHL, the researcher frequently discussed the research process and data analysis with her supervisor in an
attempt to minimize bias in the study. However, by having the background as a parent and as a teacher, the researcher had firsthand experience interacting with parents and professionals who were in the roles of family physician, ENT, audiologist, SLP, SST, and classroom teacher. Some of the implications of this study are for reading development, which is in the education field. Although the researcher was a novice, this meant that the study was conducted in the rigorous manner the researcher was recently taught. Each interview was audio recorded, and interviews were transcribed verbatim. Through separate theme analysis for each interview a voice was given to each individual participant.

**Recommendations for Future Research**

This qualitative study has revealed the need for further research to clarify the connections from otitis media through TCHL to phonological processing and eventually to learning to read. A qualitative study that could illuminate these connections is a case study in which the interviewees discuss the progress and difficulties of the same child faced with TCHL. This would allow the interaction of the same professionals with a particular family to be discussed from multiple perspectives. In addition, a longitudinal study that followed children from their diagnosis with otitis media would shed light on potential long term ramifications of TCHL due to otitis media. Finally, an epidemiological study building on the longitudinal research would answer questions about the extent to which otitis media is followed by difficulties learning to read. At present there is no system which tracks how many children with otitis media have TCHL, the severity of this loss, and the likelihood that these children experience later difficulties with reading development. Until such data are available, it appears to be unlikely that
professionals will inform parents about this possible causal chain between otitis media in the preschool years and reading difficulties in the early school years.

**Contributions of This Study and Recommendations for Future Practice**

This research has made a number of contributions to our knowledge about TCHL and reading and has revealed a number of recommendations, both generated by this researcher and by the study participants, which would benefit medical and educational professionals and parents of children with TCHL. One recommendation that arose from the study was the need to develop an easier way for the professionals from different organizational cultures to communicate. This study highlighted that the medical and educational systems operate as two distinct cultures. The medical professionals see the children one-on-one every few months, and the educational professionals see the children every day, but in group settings. The medical system communicates formally in written reports, and the educational system, while it has written reports, operates in a more informal face-to-face format. This creates different ways of operating, including different languages and assumptions, which can create barriers to communication across systems.

Each professional is responsible for one aspect of the children’s wellbeing, but the data show clearly that, in community studies, there is no one person who crosses over the entire spectrum of care. This study leads this researcher to suggest there is a need for one professional who has knowledge of the whole spectrum from otitis media onset to reading development, who can guide parents and their children with TCHL through the whole process. This would ensure that the children receive all the treatments and support they require from the medical and educational systems to minimize any repercussions of
TCHL on reading development, and to ensure clear communication between all the professionals. Given that the SLP was the only professional in the current study whose role enabled them to work in either the medical or educational systems, perhaps SLPs would be the best professionals to fill this role.

This study demonstrated that, in lieu of a professional who could guide children and parents across the medical and educational services to treat TCHL, these parents were left to become the intermediary between professionals. This suggests there needs to be a reduction in the expectation that parents are the brokers of information between professionals. This was made clear by the parent Sonia who expressed that she was expected to pass pertinent information about her son from one professional to another. Sharon, the SLP, also expressed frustration about the expectation that parents brokered the information between professionals, because information may be missed or misunderstood in this process.

This study also highlighted how little attention schools appeared to pay to noise and hearing. Thus other recommendations include hearing tests within schools, and reduction of background noises in classrooms. Olivia, the SST, was in favour of hearing tests in school as they could identify children who have TCHL, who may otherwise be missed. This process would be similar to the vision test and dental check-ups that already happen in many school boards. The reduction of background noises was recommended by Olivia (the SST), Frances (the teacher), Dr. Miles (ENT), and Patricia (the audiologist). Although the reduction of noise is essential for children with TCHL, it is a recommendation that could benefit all children in the classroom. Ways of reducing noise in schools and classrooms range from simple changes, such as learning to walk quietly
down the hallway and putting hush-ups on chairs, to more elaborate changes, such as FM sound field systems in the classroom.

The final contribution of this research is to draw attention to the importance of parent advocacy. A recommendation by many participants was for professionals to develop a better understanding of the role of parent advocates, and of the need for professionals to listen to parents, and to value them as partners. The message of parent advocacy, and being listened to by the professionals, in both the medical and educational systems was clearly stated by Sonia. Bethany, the other parent, also implied this when she said that she had a voice, and her opinion was valued by the medical professionals, because she was a nurse, not because she was a parent. The recommendation of parent advocacy was also encouraged by many of the professionals: Dr. White, Sharon, Patricia, Olivia, and Frances. Each of the professionals expressed the need for parents to stay on top of their children’s care, and to ensure the children were receiving everything they need.

Knowing that hearing loss has a causal relationship with oral language, that oral language is a strong predictor of phonological awareness, and that phonological awareness is a strong predictor of reading success, it is reasonable to expect that loss of hearing at a young age, contributes to a reading deficit. This study reinforces how critical it is for parents and professionals to be proactive and to anticipate that recurrent otitis media causing TCHL may put children at increased risk for developing reading difficulties.


Appendix A Telephone Recruitment Script for Contacting Professionals

Hi my name is Pam Briand and I am graduate student at Queen’s university starting a research study on hearing loss and reading development. I was wondering if [insert speech and language pathologist] would be willing to meet with me for 15 minutes to discuss helping me to find participants and to discuss being interviewed herself. The total time commitment of the study would be one hour. Could I set up a meeting through you for the initial 15 minutes?

If yes = Great. [Book appointment] Thank you for your time. Have a good day.

If no = Thank you for your time. Have a good day.
Appendix B Letter of Information

Dear __________.

This is an invitation to ask you to participate in a research study called Multiple Perspectives on the Connection between Hearing Loss and Reading Development, which I, Pam Briand, a graduate student in the Faculty of Education at Queen’s University, am conducting. This study was granted clearance by the General Research Ethics Board for compliance with the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans, and Queen’s policies.

The purpose of this study is to provide detailed descriptions of how medical and educational professionals communicate with parents about the reading risks associated with temporary hearing loss in preschool children due to ear infections. This study will expand research in this area by examining experiences from medical, educational and parental perspectives.

Your participation in the study will involve one individual face-to-face interview, which will be approximately 45 to 60 minutes in length and will be audio-recorded. It will take place at a location and at a time of your choice.

Participation in this research is entirely voluntary and you are free to refuse to answer any questions and to withdraw from the study at any time without concern of repercussions. If you choose to withdraw from the study you may request removal of all or part of your data. You are also under no obligation to answer any questions you are uncomfortable with. All identities will be held in the strictest confidence. I will conceal your identity and the identity of people that you might mention through the course of the interview by using pseudonyms, keeping your identity confidential to the extent possible. No individual identity will be attached to the final data produced, and no specific details will be reported that might compromise your anonymity. Only I and my supervisor will have access to the data. There are no known risks associated with participating in this study.

The results from this study will be disseminated in a thesis, and may be used in additional publications. If the data is to be used for secondary analysis it will contain no identifying information. In accordance with Queen’s policy, data will be retained for five years and then will be destroyed.

Any questions about study participation may be directed to Pam Briand at 8pb16@queensu.ca or my supervisor, Nancy Hutchinson, at 613-533-3025, or hutchinn@queensu.ca. Any ethical concerns about the study may be directed to the Chair of the General Research Ethics Board at 613-533-6081 or chair.GREB@queensu.ca.

Sincerely,

Pam Briand
Appendix C Consent Form

I ________________________. I have read the letter of information about a study being conducted by Pam Briand, of Queen’s University which explains the purpose of this research. I understand that I will be providing information for a study called *Multiple Perspectives on the Connection between Hearing Loss and Reading Development*.

I understand I will be interviewed, and that the purpose of this interview is to understand how medical and educational professionals communicate with parents about the reading risks associated with temporary hearing loss in preschool children due to ear infections. I understand that the interview will be on a one-one basis, will take between 45 to 60 minutes to conduct, and will be audio recorded. I also understand that my identity will be confidential and only Pam Briand and her supervisor will know the identity of participants.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand participation is voluntary, and I am free to withdraw at any time, and that I may request removal of all, or part, of my data. I have been given a copy of this form. I have also had this letter explained to me in person.

I hereby agree that the information obtained from this interview can be used for the purpose of preparing and presenting a master’s thesis. If any future use of this material is ever proposed, I realize I will be asked for an additional authorization at that time. If I want a copy of a summary of findings from this study I will provide an email or postal address below. I agree to participate in the study.

Any questions about study participation may be directed to Pam Briand at 8pb16@queensu.ca or her supervisor, Nancy Hutchinson, at 613-533-3025, or hutchinn@queensu.ca. Any ethical concerns about the study may be directed to the Chair of the General Research Ethics Board at 613-533-6081 or chair.GREB@queensu.ca.

**Please sign one copy of this Consent Form and return to Pam Briand. Retain the second copy for your records.**

Signature: ______________________________________

Name of Participant (Printed) ______________________________________

Email/Postal Address: ______________________________________

Date: __________________________
Appendix D Sample Interview Questions

Family physician, ENT and speech and language pathologist

1. What has been your experience in working with children who have TPHL?
2. How often do you come across children with Otitis media?
3. How significant is the hearing loss due to Otitis media in your preschool patients?
4. How does your training prepare you to identify if these children are at-risk of reading delays?
5. What are some of the strategies that have been successful in helping a child with TPHL?
6. What do you see your role as being in this process?
7. When you have a child with TPHL that you feel may be a strong candidate for reading difficulties, who do you communicate this knowledge to? Other professionals? Parents?
8. How do you communicate with the educational system regarding children who may encounter reading difficulties?
9. How do you communicate with the parents about potential reading difficulties?

Classroom teacher and student support teacher

1. What has been your experience in working with children who have had TPHL?
2. How do you learn which of your students have had TPHL?
3. What do you see as your role in this process?
4. What has been your experience communicating with medical professionals regarding hearing loss as it relates to reading difficulties?
5. What has been your experience communicating with parents of children with TPHL who have reading difficulties?

Parents

1. Could you tell me about your child who had TPHL?
2. Who were the professionals that you have worked with? Please tell me about your experiences.
3. What has been your experiences communicating with medical professionals regarding your child with TPHL?
4. What has been your experiences communicating with educational professionals regarding your child with TPHL?
5. What were you told about the relationship between your child’s TPHL and reading development? Which professionals discussed it with you?
6. What do you see as your role in this process?
7. Have you advocated for your child? If so, how?
Appendix E – Ethical Clearance

October 25, 2016

Ms. Pamela Briand
Master’s Student
Faculty of Education
Duncan McArthur Hall
Queen’s University

Dear Ms. Briand:

GREB Ref #: GEDUC-529-10
Title: “Multiple Perspectives on Hearing and Reading Development”

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled “Multiple Perspectives on Hearing and Reading Development” for ethical compliance with the Tri-Council Guidelines (TCPS) and Queen’s ethics policies. In accordance with the Tri-Council Guidelines (article D.1.6) and Senate Terms of Reference (article G), your project has been cleared for one year. At the end of each year, the GREB will ask if your project has been completed and if not, what changes have occurred or will occur in the next year.

You are reminded of your obligation to advise the GREB, with a copy to your unit REB, if applicable, of any adverse event(s) that occur during this one year period (details available on webpage http://www.queensu.ca/ors/researchethics/GeneralREB/forms.html – Adverse Event Report Form). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example you must report changes in study procedures or implementations of new aspects into the study procedures on the Ethics Change Form that can be found at http://www.queensu.ca/ors/researchethics/GeneralREB/forms.html – Research Ethics Change Form. These changes must be sent to the Ethics Coordinator, Gail Irving, at the Office of Research Services or irvingg@queensu.ca prior to implementation. Mrs. Irving will forward your request for protocol changes to the appropriate GREB reviewers and / or the GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Yours sincerely,

Joan Stevenson, PhD
Professor and Chair
General Research Ethics Board

Dr. Nancy Hutchinson, Faculty Supervisor
Dr. Lesly Wide-Woollev, Chair. Unit REB