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Childhood Hearing Loss and its Stress on Hearing Families

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Walden University
2015

Abstract

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Julie K. Macker

MEd, Columbia College, 2002

BSE, Kent State University, 1998

Dissertation Submitted in Partial Fulfillment
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Doctor of Philosophy
Special Education

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Abstract

Childhood disability increases parental stress. Research on the laterality of childhood hearing loss or presence of a cochlear implant(s) as it relates to stress in hearing parents was limited before this study. The purpose of this quantitative study was to identify relationships between the independent variables of laterality (unilateral and bilateral) of a childhood hearing loss or presence of a cochlear implant(s) and the dependent variable of stress in hearing parents. Family systems theory provided a framework for viewing each member of the family as a part of a whole, whose life events, feelings, and actions affect all of the members of the family. For this study, hearing parents of children with a hearing loss living and receiving services in the state of South Carolina rated their personal stress levels by completing an anonymous Likert-scale questionnaire. Data were collected from 151 participants via an online hosting site and analyzed using factor analysis, descriptive statistics, and ANOVA procedures. Hearing parents of children with a cochlear implant(s) (n = 37) scored the highest on all measures of stress except those measuring communication stress. Hearing parents of children with a bilateral hearing loss (n = 56) scored highest on communication stress. Hearing parents of children with a unilateral hearing loss (n = 58) scored lowest on all measures. One of the largest contributing factors to parental stress was the differing opinions educators and medical providers. The findings of this study contribute to positive social change by providing insight into how a childhood hearing loss influences stress in hearing parents. This information may help educators, service providers, and families provide better resources to the family system.

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Dedication

To my mother, Illona, who has always been my biggest cheerleader and strongest advocate. Thank you for countless hours of encouraging words through this process, but even more for 40 years of believing in me even when I wasn’t sure how to believe in myself. I love you to the moon and back!

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Last, but certainly not least, I would like to thank those parents and guardians who participated in this study for their time and responses. Thank you for the inspiration to continue to develop the field for the children you are raising and the students I teach.

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Chapter 1: Introduction to the Study

Introduction

The prevalence of hearing loss is less than one in 1,000 before the age of 18 (Mitchell, 2005). Nine out of 10 children with a hearing loss are born to hearing parents (Marschark, 1997). A hearing loss permeates all aspects of life for both the child and the family. Language, communication, and relationships are affected because of the limited or inability to hear. Educational growth may be significantly impacted due to language, communication, social, and emotional deficits (Bodner-Johnson & Sass-Lehrer, 2003; Meadow-Orlans, 1990).

Until now, researchers have examined the effects of a childhood disability on parental stress, mainly in the higher incidence disabilities including learning disabilities, intellectual disabilities, physical disabilities, and the autism spectrum disorders (Benzies, Trute, & Worthington, 2013; Karasavvidis et al., 2011; Tadema & Vlaskamp, 2009; Zaidman-Zait et al., 2010). There is limited research in the field of deafness comparatively as a whole and even less on the impact a childhood hearing loss has on a hearing family. Scholars have typically compared hearing and deaf families to identify similarities and differences. Little to no research has been conducted on the influence a childhood hearing loss has on a hearing family within the state of South Carolina. Research in this small population has the potential to effect positive social change by increasing awareness for service providers in all aspects of the child and family's development of the influence the cochlear implant status or laterality a child's hearing loss have on a hearing family. This could change the focus and efficiency of some interventions and services from child- to family-centered to become more effective in delivery, based on the presence of a cochlear implant(s) or the laterality of a hearing loss, and/or to simply generate awareness of the possible ways a hearing loss impacts a hearing family.

In this chapter, I will introduce the background of this topic of study, the research problem, purpose of the current study, and the research question and hypotheses. An introduction to family systems theory and how this theory is applied to childhood disability is provided. I will define key terms and identify the significance of this study to the discipline.

Background of the Study

A childhood disability affects the entire family including parents, siblings, extended family, and even friends. Parental stress is exacerbated by the increased need for supervision, support, and financial resources (Seligman & Darling, 2007). This increased demand results in a dissonance between the parents' desired role and their actual role and may manifest in other family members as well. Changes in familial attitudes and roles have been reported as a direct result of having a family member with a disability (Seligman & Darling, 2007). The quality of life of both the child with a disability and the other family members may be impacted by the ability of others to accept and love the child completely (Lynch & Morley, 1995).

High levels of parental stress have been found in parents of children with physical and developmental disabilities (Tefft, Guerette, & Furumasu, 2011; Trute, Herbert-Murphy, & Levine, 2007). Different stress and parental demands are identified more often when a disability is visible than when it is not (Hung, Wu, & Yeh, 2004). Physical disabilities place financial, emotional, and physical demands on caregivers and can lead to chronic depression and the need for counseling (Danino & Shechtman, 2012; Hung et al., 2004; Oelofsen & Richardson, 2006). A need to change surroundings in order to adapt to the physical, visual, or hearing needs of the child can manifest in anger, guilt, depression, and lower familial sense of coherence in parents and families of children with disabilities (Ketelaar, Volman, Gorter, & Vermeer, 2008; Lynch & Morley, 1995; Oelofsen & Richardson, 2006).

Deafness is an easily discreditable disability in that it may not be readily apparent to a lay person (Goffman, 1963; Seligman & Darling, 2007). This may make it more difficult for parents to deal with the disability, as it hinders acceptance and provokes unsupportive reactions from family members, both within the family unit and the extended family (Dyson, 2010; Seligman & Darling, 2007). Because it is a low-incidence disability, often the first time parents are exposed to any type of hearing loss is at the time of their child's diagnosis. Stress manifests in the areas of communication when parents are unable to communicate via sign language and/or the child is unable to communicate orally (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002; Zaidman-Zait, 2008). Because language affects the social development and bonding of relationships, the closeness of the family and its members may be affected by the disability (Koester, Papousek, & Smith-Gray, 2008; Nybo, Scherman, & Freeman, 1998).

In studies of parental stress as a result of a hearing loss, researchers typically examine minority groups of parents, compare parents of hearing and deaf children, and compare hearing and deaf parents, current research needs to be developed about the effect a child’s type of loss has on a hearing family’s familial stress, communication, and relationships with professionals and others outside of the home. Because it is known that the degree of a disability impacts parental stress, it is important to determine if the presence of a cochlear implant or laterality of hearing loss also influences parental stress differently. Studies in this area may impact the delivery of educational, medical, psychological, and other professional services to both children with a hearing loss and their hearing families.

Problem Statement

Researchers have noted the importance of family-centered practice for children with disabilities; yet, many services still tend to be child focused (Canary, 2008a; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Epley, Summers, & Turnbull, 2010; Hintermair, 2006; Tomasello, Manning, & Dulmus, 2010). There is a correlation between childhood disability and parental stress (Goff et al., 2013; Lynch & Morley, 1995; McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008; Seligman & Darling, 2007; Smith, Romski, Sevcik, Adamson, & Bakeman, 2011; Smith, Oliver, & Innocenti, 2001). Direct relationships between parental stress and the degree of childhood disability have also been discovered (Gelodari, Gatab, & Roshan, 2011; Ketelaar et al., 2008; Tadema & Vlaskamp, 2009). Communication between hearing families and children with hearing loss are a contributing factor of parental stress (Loots, Devise, & Jacquet, 2005; Pipp-Siegel et al., 2002; Zaidman-Zait, 2008). Parent and family responses to a childhood hearing loss indicate grief, helplessness, confusion, and concern for the development of relationships with peers (Fellinger, Holzinger, Beitel, Laucht, & Goldberg, 2009; Freeman, Dieterich, & Rak, 2002; Nybo et al., 1998). While the potential importance of family-centered practice is known, without the knowledge of if and how a childhood hearing loss influences parental stress as viewed through family systems theory, service delivery to this population may not be as supportive or effective as desired. In this study, I investigated if and to what degree the stress levels of hearing parents were influenced by a cochlear implant(s) or the laterality of a childhood hearing loss and provided information that will enable educators and service providers to better serve parents and families of children with hearing loss.

Purpose of the Study

The purpose of this study was to examine whether the added responsibilities, communication issues, and relationships with family and service providers influence stress in hearing parents of children with a hearing loss and to determine if this differed by the laterality of the hearing loss or presence of a cochlear implant(s). Researchers who have studied parenting students with cognitive and physical disabilities have indicated that the more involved the disability, the more reports of parental stress increase. The Americans with Disabilities Act (ADA) defined a disability as “a physical or mental impairment that substantially limits one or more major life activities” ("Americans with Disabilities Act of 1990, Pub. L. No. 101-336," 1990). For the purpose of the current study, hearing loss was considered a physical disability, as it limits the ability to hear, but does not limit intellectual capacity.

Caring for a child with a disability places physical, emotional, and financial burdens on parents, resulting in increased stress, negative emotions, and adverse effects on the social life of the family (Brehaut et al., 2004; Karasavvidis et al., 2011; Stabile & Allin, 2012; Tefft et al., 2011). Caring for a child with a physical disability places physical, emotional, and financial burdens on parents. When compared to parents of typically developing children, parents of children with a disability report poorer well-being and are at risk of physical and mental health problems, such as clinical depression (Karasavvidis et al., 2011; Oelofsen & Richardson, 2006; Stabile & Allin, 2012).

Employing quantitative procedures, I examined parental stress across three subcategories and compared these subcategories across three groups based on the type of childhood hearing loss. The independent variables for this study were the presence of a cochlear implant(s) and the laterality of the child's hearing loss: unilateral or bilateral. The dependent variables of stress for this study were general parental stress, communicative stress, and relationship stress. The population for this study was hearing parents of children from birth through 21 years of age who were receiving early intervention or educational services for a hearing loss within the state of South Carolina. A lack of parental knowledge of hearing loss, poor support systems, and feelings of helplessness and confusion contribute to stress of hearing parents (Calderon & Greenberg, 1999; Nybo et al., 1998; Young & Tattersall, 2007). Scholars have found no significant differences in family functioning between those with a hearing loss and those without (Fisiloglu & Fisiloglu, 1996). Until this study, no research had been done to determine if the laterality of hearing loss or cochlear implant status of a child had influence on the stress levels of hearing parents. The lack of research in this area generated a gap that, when filled, may impact the delivery of educational, medical, psychological, and other professional services to both children with a hearing loss and their hearing families.

Include a topic sentence. A childhood disability affects parental stress (Goff et al., 2013; Karasavvidis et al., 2011; Lynch & Morley, 1995; McConkey et al., 2008; Neece, Green, & Baker, 2012; Seligman & Darling, 2007; Smith et al., 2011; Smith et al., 2001). Direct relationships between parental stress and degree of disability and needs of the child have also been discovered (Gelodari et al., 2011; Goff et al., 2013; Ketelaar et al., 2008; Tadema & Vlaskamp, 2009). There is limited research on parental stress and childhood hearing loss, and scholars have not examined the differences in parental stress based on the laterality of the child's hearing loss. Because the degree of other types of disabilities is directly related to the levels of parental stress, it is important to determine what relationship exists between presence of cochlear implant or laterality of a childhood hearing loss and the stress levels of hearing parents.

Research Questions and Hypotheses

Research Question

The specific research question for this study was

1. What relationship existed among the independent variables of a unilateral childhood hearing loss, a bilateral childhood hearing loss, and a child with a cochlear implant(s) and the dependent variables of parental stress, communicative stress, and relationship stress?

Hypotheses

$H_1$1 There was a difference in stress levels amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_1$2: There was a difference in communicative stress amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_1$3: There was a difference in relationship stress amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_1$4: There was a difference in total instrument scores amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

Null Hypotheses

$H_0$1: There was no difference in stress levels of hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_0$2: There was no difference in communicative stress levels of hearing parents among unilateral, bilateral, and cochlear implant groups..

$H_0$3: There was no difference in relationship stress levels of hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_0$4: There was no difference in total instrument scores of hearing parents among unilateral, bilateral, and cochlear implant groups.

Theoretical Framework

Family systems theory is a lens for examining the family as a unit as opposed to individual members. Family systems theory, also known as Bowen theory, was developed in the 1950s and 60s by Bowen who determined that each person in a family unit is “not an autonomous psychological entity," but is "strongly influenced by the family relationship system" (Kerr & Bowen, 1988, p. ix). Each member of the family lives and functions within the larger system and should not be treated as independent of the family unit (Atwood, 2001). When one member experiences a physical or psychological problem, treatment should be directed at the family as a whole, not just the symptomatic person (Atwood, 2001; Lynch & Morley, 1995; Skyttner, 2006). Positive outcomes have been reported when the family is more involved in therapies and treatment instead of only the child with the disability (Hill-Weld, 2011; Smith et al., 2011; Williams, Berthelsen, Nicholson, Walker, & Abad, 2012), Family systems theorists also emphasize the importance of the relationships between all family members, not just that of parent and child (Goldenberg & Goldenberg, 2003; Seligman & Darling, 2007; Turnbull & Turnbull, 2001). Family structure, family interactions, and family functions play roles in the development of all its members (Canary, 2008a; Seligman, 1999; Seligman & Darling, 2007; Stabile & Allin, 2012).

Family systems theory is one way of examining families of children with special needs. Seligman and Darling incorporated the work of Turnbull and Turnbull (1986, 2001) who asserted the child does not grow up in isolation, an important fact for professionals working with children with any form of disability or sensory impairment. Turnbull and Turnbull stressed the importance of a holistic view of family life through the family systems theory. Family structure can affect the way families adapt to disabilities (Benzies et al., 2013; Canary, 2008a; Seligman, 1999; Trute, Benzies, & Worthington, 2012). Family interactions can be affected by a disability, as the normal ebb and flow of communication is disrupted (Arnold, Heller, & Kramer, 2012; Goldenberg & Goldenberg, 2003; Hannah & Midlarsky, 1985; Seligman & Darling, 2007; Smith et al., 2011). Family functions change as the result of the financial burdens, time constraints, coping development, and role responsibilities that a childhood disability introduces (Braden, 1994; Karasavvidis et al., 2011; Seligman, 1999; Seligman & Darling, 2007). A more detailed explanation of family systems theory is provided in Chapter 2.

Family systems theory, as it relates to a childhood disability, provided a construct for this investigation into hearing families of children with hearing loss. The greater the disability, the higher the levels of parental stress and familial impact. When examining parental stress and childhood hearing loss, levels are generally compared against other disabilities, groups with no disabilities, or between parental hearing statuses. The purpose of this study was to examine the stress of hearing parents in the three subcategories of parental stress, communication stress, and relationship stress and analyze them across groups based on whether the child had a unilateral hearing loss, bilateral hearing loss, or a cochlear implant(s). The greater a disability is in general, the greater the need is for more family-specific interventions. Therefore, the findings of this study may help impact service delivery to families of children with a hearing loss, taking into account the influence of the cochlear implant status or laterality of the hearing loss.

Nature of the Study

This study consisted of a survey for which I employed quantitative ANOVA procedures. The use of a convenience sample and a lack of a control group eliminated the use of an experimental design. Given the anonymous nature of the survey, qualitative follow-up interviews were not possible, thus eliminating a mixed-methods approach. I was known in some areas of the small population; therefore, anonymity was developed to reduce the possibility of influencing responses. Most research in the area of deaf children and hearing parents exists in the qualitative paradigm, warranting more research in the quantitative paradigm.

The population for this study was hearing parents/guardians of at least one child with a hearing loss, aged birth through 21, and enrolled in an early intervention or educational setting within the state of South Carolina. There were approximately 1,100 students enrolled in these programs across the state. A convenience sample was used, drawn from the population of hearing parents of students meeting the above criteria. Given that about 90% of students with a hearing loss live in a home with hearing parents, the size of the population was the parents/guardians of approximately 990 students. An a priori test for linear multiple regression was conducted using G Power 3. Statistical Software was run with the alpha at 0.05, power at 0.95, and a medium effect size at 0.15. The analysis indicated a minimum sample size of 138 subjects. This number of subjects supports the required number for an exploratory factor analysis (EFA) following the Rule of 100 and the Rule of Five. It was not important to make the effect size small for this study; therefore, a medium effect size of 0.15 was chosen. More information about this effect size choice and the required numbers for EFA will be provided in the review of the pilot study in Chapter 4.

Data collected included eight questions about general stress, eight questions about communicative stress, and eight questions about relationship stress. The independent variables in this study were the presence of a cochlear implant(s) and the laterality of childhood hearing loss. The laterality of hearing loss was unilateral or bilateral. The dependent variable was parental stress, which was divided into three subcategories of parental stress, communicative stress, and relationship stress. The instrument, The Influence of Childhood Hearing Loss on Family Stress, was an adapted version of a questionnaire, The Impact of Childhood Hearing Loss on Family, used in research conducted in 1990 with a similar purpose.

An online link to the questionnaire was distributed to executive directors of special education programs in the state's public and residential schools for dissemination to teachers of and directly to hearing parents of children with a hearing loss. In addition, this link was also delivered to statewide programs serving families of school-aged children with a hearing loss for distribution to parents. The link to the online questionnaire was also advertised via parent newsletters and a national agency website that hosts research opportunities by state. This study took place over an 8-week time frame from mid-November 2014 through early January 2015. Data were analyzed using SPSS software. A factor analysis was run to determine which factors loaded into categories, to generate latent scores used in ANOVA analyses, and to identify which factors accounted for the largest variance. Descriptive statistics included means and standard deviations for all three subsets of stress and for the three categories of hearing loss. ANOVA and Post-Hoc Tukey tests were run to determine if there were statistically significant differences between the three groups on the measures of stress based on total observable scores and total latent scores.

Definition of Terms

The following terms are defined for better clarity and understanding as they related to the purpose of this study.

Bilateral loss: Hearing loss in both ears (Schow & Nerbonne, 2007).

Cochlear implant: A device surgically implanted in the cochlea of individuals with significant hearing loss that provides electronic stimulation to the auditory nerve, providing sound and speech information (Schow & Nerbonne, 2007).

Communication stress: Stress derived from parental concerns about the difficulty of communicating with a deaf child, including the child in family conversations, and success in acquiring special skills and techniques for improving language and communication at home and at school (Meadow-Orlans, 1990).

Early intervention: Encompasses services provided to children with disabilities and their families from birth to age 6 (South Carolina Department of Disabilities and Special Needs, 2013).

Hearing loss: Hearing sensitivity levels of 21 decibels and up (Schow & Nerbonne, 2007).

Normal hearing: Hearing sensitivity levels up to and including 20 decibels (Schow & Nerbonne, 2007).

Parental stress: Stress from parental feelings of grief, sorrow, guilt, or anger over a child’s disability and as a result of the level of parental satisfaction with the child’s current performance and future prospects (Meadow-Orlans, 1990).

Relationship stress: Stress resulting from relationships between parents and professionals who provide services for the special needs of the deaf child including members of the medical profession, educators, and family members not living in the home (Meadow-Orlans, 1990).

Unilateral loss: Hearing loss in one ear with normal hearing in the other ear (Schow & Nerbonne, 2007).

Assumptions

One assumption of this study was that the participants answered the survey questions in an honest manner. Participation in this study was voluntary and anonymous. Procedures for confidentiality, as mandated by Walden University's Institutional Review Board (IRB), were followed. Participants were provided with informed consent and knowledge that they may choose to withdraw from the study at any time prior to the electronic submission of responses. Given the anonymity of responses, it was impossible to withdraw from the study after the survey was submitted. If interested, participants were able to request findings of the study to gain more insight into the influence of childhood hearing loss on parental stress. This was done through an e-mail submission link that was not directly connected to survey responses.

Delimitations

This study was delimited to hearing parents whose children were age birth through 21, had a hearing loss, and were being served in an early intervention or educational setting within the state of South Carolina. Hearing parents of children with a hearing loss who fell outside of these guidelines were excluded from this study. Parents with a hearing loss were not included in this study.

This study was delimited to the examination of parental stress as it related to having a child with a hearing loss. Stress was measured with a self-reporting, Likert-type scale adapted from an instrument previously designed to examine hearing parents' stress related to the parenting demands of having a child with a hearing loss. The results of the study are generalizable to parents who are hearing and have a child with a hearing loss ages birth through 21 who are enrolled in an early intervention or educational setting within the state of South Carolina. The results of this study are not generalizable to hearing parents of children with a hearing loss outside of this age range, educational setting, or the state of South Carolina.

Limitations

The limitations of this study include the inability to generalize results to other regions, as only data from South Carolina was included. The self-reporting measure of the questionnaire may have led to responder attrition. It was hoped that the anonymous nature of the survey helped to combat this. The anonymity of the survey also helped resolve the fact that some participants may have known me, thereby reducing social desirability and acquiescence biases. Response rates and incomplete surveys provided another limitation to the study. In addition, there is limited research on childhood hearing loss and the stress levels of hearing parents for comparison.

Significance of the Study

The results of this study have the potential to affect hearing parents of children with a hearing loss living and receiving early intervention and educational services within the state of South Carolina as well as educators and service providers who work with this population. Knowledge of how the presence of a cochlear implant(s) or laterality of a childhood hearing loss influence parental stress could potentially impact service delivery for these students, their parents, and their families. The results of this study provided opportunity for social change in the area of policy and practice when working with children with hearing loss and their families. Implementing a family-centered focus of educational and service provisions may be just one missing link to improving not only the delivery of services, but quality of life for all involved individuals.

Summary

Ninety percent of children with a hearing loss are born to hearing parents with no prior knowledge of deafness or the impact it may have on daily life including education, social interactions, and communication (Marschark, 1997). Educational programs may not fully address the needs of the family during the critical years of their child's development. Research investigating the impact of a childhood disability on the family exists, but in limited quantities for the area of deafness and hearing loss. There is a need for investigation into this realm so services provided to this population may be tailored to address the issues in a more effective manner.

I used Seligman and Darling's family systems theory and childhood disability as a theoretical construct for parental stress in relation to a childhood hearing loss. In Chapter

2, I reviewed the literature as it relates to childhood disability, parental stress, communicative stress, relationship stress, and a childhood hearing loss. Chapter 3 provides an outline of the research design and methodology, instruments and materials, data collection, and the analysis of the data. Chapter 4 includes research results and findings conducted after the analysis of the data. Chapter 5 contains a summary of the outcomes, conclusions from the study's completion, and the significance of the study to social change.

Chapter 2: Literature Review

Introduction

More than 90% of children with hearing loss are born to hearing parents with little to no knowledge of this disability and how it can impact the family (Marschark, 1997, 2008). While the potential importance of family-centered practice is known, without the knowledge of whether a childhood hearing loss influences parental stress, service delivery to this population may not be as supportive or effective as possible. The intent of this study was to reveal whether the added responsibilities, communication issues, and relationships with family and service providers factor into stress levels of hearing parents of children with a hearing loss. This literature review includes various themes relevant to working with parents of children with disabilities, particularly those concerned with stress, communication, and relationships with professionals and other individuals not living within the home environment. Investigating these themes is vital to developing a greater understanding of how a disability, specifically a childhood hearing loss, affects the family as a whole, functioning unit, or system; this is a key to developing programs and providing services that meet the needs of this unique population.

The purpose of this chapter was to provide a review of the professional literature relevant to this study on how the presence of a cochlear implant(s) or the laterality of a child's hearing loss may influence the stress of hearing parents. In this literature review, I focused on the major themes of family systems theory, impact of a disability on family stress, communication, and relationships, hearing loss and the impact of hearing loss on family. There is a need to address the influence a childhood hearing loss has on hearing parents. Seligman and Darling's framework for family systems theory and childhood disability appears in a section that addresses the conceptual framework. This study was based upon this conceptual framework.

Literature Search Strategy

In this section, I present a systematic review of significant seminal and current peer-reviewed literature. Online databases used include Academic Search Complete, Education: a SAGE full-text database, Education Research Complete, Expanded Academic ASAP, ProQuest Central, PsychINFO, and Psychology: a SAGE full-text database from the Walden online library, the University of South Carolina online library, and the Columbia College online library. In addition, Google Scholar, Walden eBrary, and print sources were used. Search terms included individual and various combinations of the following: *parent, parental, family, familial, home, needs, prefer, language, sign language, American Sign Language, ASL, linguistic, develop, social cognition, early intervention, stress, communication, partnerships, relationships, professionals, service providers, services, infant, toddler, elementary, middle, high, young adult, deaf, hard of hearing, degree of loss, cochlear implant, cochlear implants, CI, unilateral, bilateral, audiology, audiological, linguistic minority, disability, childhood, family-centered, delivery,* and *model.* Given the limited research for this population, it was necessary to investigate the impact of disabilities other than deafness on the family. This added the terms *physical, intellectual, sensory, autism, autistic, Down syndrome, blind, deaf-blind, mental,* and *parental perceptions* to the list of search terms. I attempted to limit research to the last 5 years, but given the limited amount of research for this population, it was necessary to also include older and seminal literature outside of those guidelines.

Theoretical Framework

Family Systems Theory

The family system is a natural system, in that it exists in nature independently of humans creating it (Atwood, 2001). It is an emotional system including a network of interlocking relationships (Atwood, 2001). Family systems theory was derived from systems theory, which was established to understand everything as part of a greater whole and not independent of an integrated system (Skyttner, 2006). According to family systems theory, each member of the family should not be treated independently of this unit because he or she exists and functions within the larger system (Atwood, 2001). The function of the individual is incomprehensible without relation to the context of the group to which he or she belongs. The emotional and social functioning of every member within the family plays a part in any physical or psychological difficulty of another, and treatment should not be only directed at the person displaying symptoms, but the family as a whole (Atwood, 2001; Lynch & Morley, 1995; Skyttner, 2006). These implications were of key importance to this study because I examined the influence of a childhood hearing loss on the family in hopes of generating information for professionals seeking to effect social change in delivery of services.

Family Systems Theory and Childhood Disability

Family systems theorists reject that the only important relationship is that of mother and child and makes the case for interrelatedness of all family members; that is, if one member is affected, all members in the system are as well (Goldenberg & Goldenberg, 2003; Hill-Weld, 2011; Seligman & Darling, 2007; Turnbull & Turnbull, 2001). In order to understand family interactions, it is imperative to understand the structure of the family unit and the relations of each member within the unit (Seligman, 1999; Seligman & Darling, 2007).

Family structure. The structure of a family encompasses membership characteristics, cultural factors, and ideological style (Seligman, 1999). Membership characteristics are constantly changing over time. Births, deaths, moving in or out of specific family members, loss of job, and introduction of a disability stimulate a pattern of responses that were not previously apparent (Seligman, 1999; Turnbull & Turnbull, 2001). Religious, ethnic, racial, and socioeconomic status can affect cultural beliefs. These cultural beliefs then influence the way families adapt to childhood disability (Canary, 2008a; Seligman, 1999; Seligman & Darling, 2007). The ideological style of a family is shaped in part by the family's belief system, values, and coping abilities. A child with a disability forces the family to confront beliefs about people with disabilities (Seligman, 1999). The family's response may initially be shaped by their value system which, in turn, may ultimately end up being altered by the child over time (Seligman & Darling, 2007).

Family interactions. Family interactions include those between parents, parents and children, siblings, extended family members not living in the home, and relationships formed with service providers. The presentation of a disability into the family unit alters the normal pattern of family interactions and typical family relationships (Arnold et al., 2012; Hannah & Midlarsky, 1985). Communication breakdowns occur within a family as a result of a faulty family system, not faulty people (Seligman, 1999; Seligman & Darling, 2007). Family interactions occur within two types of family systems: open and closed. Open systems accept communication to and from those outside of the family unit, whereas closed systems have rigid boundaries limiting who is and is not welcome to communicate with the family (Goldenberg & Goldenberg, 2003; Seligman & Darling, 2007). Family interactions and communication hold keys to understanding families of children with disabilities because it is not uncommon for a childhood disability to be blamed for family problems that arise as a result of communication breakdowns.

Family functions. The roles and functions of each and every family member are affected by a disability within the family unit (Jones, Hastings, Totsika, Keane, & Rhule, 2014; Seligman, 1999; Seligman & Darling, 2007; Williams et al., 2012). A child with a disability introduces extra stress into the family system which, in turn, can impact the family negatively (Braden, 1994; Karasavvidis et al., 2011; Seligman & Darling, 2007). Financial concerns, personal time, and career decisions are all affected when a child with a disability is introduced into the family system. When family members are able to take on roles of other members, the development of coping skills begins. Positive changes in family attitudes and roles are sometimes reported as a direct result of a family member with a disability (Seligman & Darling, 2007).

Impact of Disability on Family

A critical aspect of developing as a family is parent-infant bonding, and while a child is able to live with a specific condition, the quality of life may be more greatly affected by the parents’ ability to accept the whole child (Lynch & Morley, 1995; Seligman & Darling, 2007). Because parents anticipate their child’s development to follow conventional norms, the initial response to a disability is often shock (Abdelmoktader & Abd Elhamed, 2012; Seligman, 1999; Seligman & Darling, 2007). Some studies reported a higher level of parental stress and family malfunctioning as a result of a childhood disability (Karasavvidis et al., 2011; Ketelaar et al., 2008; McConkey et al., 2008; Smith et al., 2001). An inverse relationship has been found between parental stress and overall family adjustment (Benzies et al., 2013). Other studies found no difference in daily events, family cohesion, and family functioning between families with and without children with disabilities (Cuzzocrea, Larcan, Costa, & Gazzano, 2014; Dyson, 2010; Seltzer et al., 2009).

Characteristics of disabilities cover a wide spectrum and often come with some form of stigma. Some disabilities are identified as “discreditable,” or not readily apparent to a lay person (Goffman, 1963; Seligman & Darling, 2007). A physical disability easily concealed by clothing might be able to “pass” in a great deal of social situations, thereby avoiding stigma; whereas a more apparent disability, such as Down syndrome, would be identified almost immediately (Seligman & Darling, 2007). A study of children with physical disabilities found that perceived competence was higher for those who were more active than those who were not (Barg, Armstrong, Hetz, & Latimer, 2010). Intellectual disabilities are often unseen disabilities, until introduced into the educational or work setting. A study of students with mild intellectual disabilities revealed that students felt stigmatized in both the community and school setting and related better to peers with disabilities than non-disabled peers (Cooney, Jahoda, Gumley, & Knott, 2006). Language and sensory disabilities often create stigmas in the area of communication, which impacts greatly upon interaction with peers as well as family (Smith et al., 2011). Family involvement is essential to the development of children with disabilities and outcomes are dependent upon this participation (Danino & Shechtman, 2012; Jones et al., 2014; Kanaka Durgamba, Parthasarathi, & Murty, 2004; Kyno et al., 2013; Williams et al., 2012). A child's development is impacted not only by the disability itself, but by the reactions of family members to the disability (Tomasello et al., 2010). It is more likely that children with developmental delays live in a family setting with higher levels of parental stress than children without disabilities (Neece et al., 2012). A child's developmental limitations may be influenced by stress, communication, and relationships formed with service providers and other support structures (Dempsey et al., 2009; Epley, Summers, et al., 2010; Tomasello et al., 2010). It is in these ways Family Systems Theory is related to this study. The investigation of the influence a childhood hearing loss has on a hearing family's stress helps to build upon Family Systems Theory as it relates to a childhood disability as well as contribute to the limited pool of research available for this population.

Parental Stress

General Stress

Studies of the impact a childhood disability has on parental stress have provided varied results. Studies on stress as a result of a childhood disability were more often conducted with mothers than fathers, possibly due to the fact that the burden of care falls on mothers. Additionally, measures of stress often elicited more significant responses in mothers than fathers, likely because a childhood disability affects the domain in life with which mothers identify more strongly (Dabrowska & Pisula, 2010; Gerstein, Crnic, Blacher, & Baker, 2009). Mothers of children with disabilities report that their role often extends beyond the usual family responsibilities and boundaries, as they have to cover service, education, and advocacy needs of their children (Benzies et al., 2013). The age of the maternal parent has been found to be a significant predictor variable of family adjustment, with the higher ages predicting a higher level of positive adjustment (Trute et al., 2012). Research has shown that daily stress from the demands and challenges of parenting plays a critical role in the psychological and developmental welfare of children (Abdelmoktader & Abd Elhamed, 2012; Crnic, Hoffman, & Gaze, 2005; Deater-Deckard, 2005; Gerstein et al., 2009; Hill-Weld, 2011; Jones et al., 2014; Sardar & Kadir, 2012). The review of literature focusing on stress is comprised of studies conducted with families of children with intellectual disabilities, profound intellectual and multiple disabilities, Down syndrome, motor impairments, developmental delays, mental retardation and/or chronic illness, autism spectrum disorder, learning disabilities, and cerebral palsy. Sources of stress identified fell into three main categories: time demands, behaviors, and personal sacrifice/feelings.

Time demands. Parental stress is significantly impacted by the personal and familial demands a childhood disability places on time. Family functioning appeared to play more of a role in parental stress than does the development of the child with a disability (Karasavvidis et al., 2011; Ketelaar et al., 2008; Smith et al., 2001). There was a direct relationship between the level of needs of the child and the level of stress of parents (Tadema & Vlaskamp, 2009). An inverse relationship was discovered between the level of parent well-being and the level of parental stress (Burke & Hodapp, 2014; Warfield, 2005). In addition, families reported that the younger the child was, the lower the level of support for families and the older the child, the higher the levels of stress (Gelodari et al., 2011; Tadema & Vlaskamp, 2009).

Behaviors. Difficult and demanding behaviors in children with disabilities directly relate to parental stress levels (Jones et al., 2014). George, Kid, & Brack (2011) discovered that two-thirds of referrals for mental health services for children with learning disabilities were based on challenging behaviors, which is linked to higher parental stress and results in more family problems. Depressive symptoms in parents whose children attended weekly applied behavioral therapies were revealed to be inversely related to the number of hours and intensity of services per week, whereas the level of parent involvement was directly related to perceived personal strain (Schwichtenberg & Poehlmann, 2007). It should be noted, however, that regardless of the presence of a disability, children who demonstrated behavior problems created greater stress in mothers than fathers (Floyd & Gallagher, 1997). In a study of parents and siblings of children with and without disabilities, a relationship between family functioning and behavior problems was only found in fathers of children with disabilities (Cuzzocrea et al., 2014). Another study of children with and without disabilities found that while both behaviors and parental stress decreased over time, the levels of both were significantly higher in the group whose children had developmental delays (Neece et al., 2012). In addition, parental stress is both a predictor and outcome of child behavior problems, and vice versa (Neece et al., 2012). Zaidman-Zait, Mirenda, Zumbo, Wellington, Dua, & Kalynchuk (2010) used the Parental Stress Inventory, Short Form (PSI-SF), with children with autism spectrum disorders, and found that only the parental distress subscale was accurate and should therefore be used with cautiously with children with autism and, possibly, other disabilities.

Personal sacrifice/feelings. Maternal and paternal beliefs and values can have a substantial impact on perceived stress. Fathers' stress was higher in families where a lack of adequate child care existed, quite possibly because of the higher level of active involvement thus required (Warfield, 2005). Fathers also scored higher on coping scales than did mothers (Twoy, Connolly, & Novak, 2007). A cross-sectional analysis of acceptance and maternal stress found that acceptance has a negative association with maternal stress, depression, and anxiety and may therefore be a predictor of parental distress (Lloyd & Hastings, 2008). Childhood disability was found to directly affect maternal health and place stress on relationships with other caregivers in the home (Stabile & Allin, 2012). In addition, higher parental stress is directly related to the depressive feelings and pain levels of the children with disabilities and lower coping resources available to the parents (Cramm & Nieboer, 2011).

Significance. A better understanding of parental stress may help empower parents to develop skills needed to participate actively in the education and development of their children while also identifying areas needing to be addressed by service providers of these same children (Goff et al., 2013; Zaidman-Zait, 2008). A study conducted on the implementation of a parent training program found that total perceived parental stress was significantly lowered (George et al., 2011). Another study focusing on parent empowerment found that parents who were more connected to service providers and more informed of the disability and needs were more trusting and less defensive (Murray, Handyside, Straka, & Arton-Titus, 2013). The frustrations parents of children with a hearing loss experience on a daily basis “may leave parents with a diminished sense of competence and satisfaction and my eventually have an adverse effect on the quality of parenting, the parent-child relationships, and the child’s functioning” (Zaidman-Zait, 2008, p. 140). Family-centered services that address the needs of both the child and the family may help mediate these adverse effects, but first determining how a childhood hearing loss impacts the family was imperative.

Communication Stress

The review of literature focusing on communication is comprised of studies conducted with families of children with learning disabilities, complex communication needs, physical disabilities, juvenile idiopathic arthritis, and mild to moderate unspecified disabilities. “Communication is vitally important to any family, but especially when there is a child with a disability” (Seligman & Darling, 2007, p. 37). Studies of the impact a childhood disability has on communication provide insight into language and literacy development, social skill development, and interfamilial communication.

Language and literacy development. Speech problems have become the primary chronic condition causing limitation to daily activities (Halfon, Houtrow, Larson, & Newacheck, 2012). Results of research conducted on the home environment of children with disabilities suggest that specific aspects of the environment can positively or negatively impact literacy interactions between parents and children (Dolzal-Sams, Nordquist, & Twardosz, 2009). A study of archival data revealed that there was no difference in the frequency of home literacy activities for children with and without disabilities. A higher level of emergent skills were noted for the typically developing group of children, but the home literacy experiences of children with disabilities should not automatically be perceived as impoverished (Breit-Smith, Cabell, & Justice, 2010). When parents of toddlers with developmental delays were provided language intervention tasks, there was no significant difference in parental stress pre and post intervention, but parental stress was twice as likely to decrease when the child's expressive language increased (Smith et al., 2011).

Social skill development. A factor analysis of a variety of scales as completed by caregivers determined that emotional self-efficacy and impact of the disability on the family were the strongest predictors of participation in everyday activities for children who required the use of augmentative communication (Clarke et al., 2011). A study of parents and teachers of children with mild-moderate or severe disabilities found a direct relationship between high level of parental involvement and greater social skills development in children, which supported prior research suggesting that the level of parental involvement is directly affected by the severity of a child's disability (Bennett & Hay, 2007; Dallas, Stevenson, & McGurk, 1993). Of crucial importance to the development of social skills are family interactions and communication (Canary, 2008b; Karasavvidis et al., 2011).

Interfamilial communication. When two groups of adolescents, one with and one without learning disabilities, and their parent(s) were given the Family Relationships and Communication Scales assessment, the level of communication was reported as much lower by the adolescents than as perceived by parents. The parents of the group of youth with learning disabilities reported higher problematic involvement in family and values and behaviors than in the non-learning disabled group (Heiman, Zinck, & Heath, 2008). Interviews of families of children with juvenile idiopathic arthritis, a chronic disorder with no cure, revealed that increasing sibling awareness can help improve family communication and reduce behavior problems in siblings (Waite-Jones & Madill, 2008). Other research indicates that siblings of children with disabilities want to be involved and not excluded from information and concerns related to the disability (Arnold et al., 2012). Another examination of families revealed that adults often attempt to reduce the effects of a childhood disability on family members and daily life, rather than establishing family discussions about any issues, positive or negative, resulting from the disability (Canary, 2008b). A study of 139 adult siblings of individuals with developmental disabilities reported that the siblings felt left out of the definition of "family" that seemed to only include parents, which led to less understanding of services, education, and the disability itself (Arnold et al., 2012).

Significance. It is imperative for service providers to consider the importance of home literacy experiences and emerging literacy skills of young children with disabilities when making clinical recommendations (Breit-Smith et al., 2010). "Establishing effective communication between families and their young children has long been recognized as the key to early language acquisition, family functioning, and overall development of the child with a hearing loss" (Sass-Leher & Bodner-Johnson, 2003, p. 69). Understanding the effect a childhood hearing loss has on communication within the home environment is of key importance to service providers seeking to help establish said effective communication.

Relationship Stress

Relationships with individuals outside of the home are crucial for families of children with disabilities. These relationships fall into categories of education, service providers, and family members and friends who do not live within the home. Social supports can be the make-it or break-it factor in a great deal of families dealing with a childhood disability (Seligman & Darling, 2007). The literature review on the impact a childhood disability has on relationships includes research conducted on families of children with intellectual disabilities, developmental disabilities, children receiving Medicaid for a variety of disabilities, cerebral palsy, chronic illness, vision or hearing problems, and fetal alcohol syndrome.

Education. While it is well known that educators are under extreme pressure with high stakes testing and other measures of accountability, there needs to be a balance between educational outcomes and quality of life for students and families with disabilities (Turnbull, Turnbull, Wehmeyer, & Park, 2003). An examination of ways to provide support to families of children with disabilities suggested that teachers and professionals in the education sector could play a significant role in enhancing the quality of life of the entire family (Van Haren & Fiedler, 2008). Lower parental stress was found for mothers who reported good to excellent relationships with their child's schools (Burke & Hodapp, 2014). Investigation into the role of administrative structures of two early intervention program sites indicated differences in management of resources and delivery of services between a school district and a community based non-profit child development center which, in turn, played a key role in effective family-centered practice (Epley, Gotto, et al., 2010). A study examining parents of children with disabilities before an after a 16 week empowerment program with special education teachers revealed that parents felt teachers viewed their child as a job and not an individual, that teachers did not view the parent as a contributor, and that they as parents felt the need to be defensive because of these issues (Murray et al., 2013).

Service providers. Studies have shown that often families feel the services for their child with a disability are adequate, but the lack of supports offered to the family and the confusing processes of attaining assistance are a significant problem (Doig, McLennan, & Urichuk, 2009; Summers et al., 2007). Greater satisfaction with services was reported with lower levels of parental stress (Williams et al., 2012). A study of archival data of 14,500 children in New Zealand found that only 5,600 of the children's families were given a needs assessment, meaning 8.700 never had one and were thereby not provided opportunities to obtain familial help (Clark & MacArthur, 2008). Sufficiency of services was determined to be a significant predictor of quality of life in families with a child in early intervention and early childhood settings (Hughes & Valle-Riestra, 2012; Summers et al., 2007). Top-down structuring of services, inter-professional rivalries, and unmatched professional philosophies within the establishments providing services provide challenges for the delivery of services that are truly family-centered (Dodd, Saggers, & Wildy, 2009). A high direct cost of services is a source of stress for parents (Stabile & Allin, 2012).

The level of trust parents and guardians of children with disabilities have in healthcare providers decreased as their children got older (Chen & Boothroyd, 2006). Parents who were more informed about their child's needs and disability became more trusting of service providers (Murray et al., 2013). Parents who received more empathetic attitudes from physicians reported higher levels of satisfaction and better overall long-term perceptions of their child (Abdelmoktader & Abd Elhamed, 2012). The level of support needed by families also decreased over time when family-centered services were provided at an early age, as parental stress, family adjustment, stability, and self-esteem increased (Kyno et al., 2013; Trute, Hiebert-Murphy, & Wright, 2008). A study of 16 families of children with a variety of disabilities found that parents often relied on recommendations of others to obtain services of which the parents were unaware existed (Ceglowski, Logue, Ullrich, & Gilbert, 2009). Similarly, a study of parents of children with autism found that 56% of parents relied solely on information from their primary care physician as a means of obtaining additional services or determining options for their child (Twoy et al., 2007). Coordination of outreach efforts within the community, including at the time of diagnosis, would certainly help increase family awareness of and access to childcare and other coordinated assistance (Ceglowski et al., 2009; Goff et al., 2013; Harnett, Tierney, & Guerin, 2009).

Family/friends outside the home. For children with disabilities, a moderate relationship was found between acceptance from peers and a positive self-concept, suggesting acceptance and friendship from a peer group can be highly motivating for students with disabilities (Pijl & Frostad, 2010). Comparably, when parents had an opportunity to interact with other parents of children with disabilities, their satisfaction and perceived quality of social environment increased, indicating that overall satisfaction is inversely related to perceived stigmas (Green, 2001). A study of coping strategies used by parents of children with autism revealed that 93% of parents sought support from other families with similar problems (Twoy et al., 2007). A parental training program focusing on increasing parental knowledge and positive parent-child interactions and decreasing parental stress and negative child behaviors resulted in greater group discussions and connecting parents of children with similar problems (George et al., 2011).

The presence of a childhood disability has been found to provoke unsupportive responses and reactions from extended family members (Dyson, 2010). Family resources proved to be a stronger predictor of stress than perceived family support or stressful life events (Smith et al., 2001). Social supports can change the way individual members of families deal with the presence of a disability (Seligman & Darling, 2007). Some siblings felt left out of the process, as most supports were designed for parents only, not the whole family (Arnold et al., 2012)

Significance. Collaboration is important for the success of children with disabilities and their families (Turnbull & Turnbull, 2001). Understanding the family support system will enable others to provide better resources and improve services to families (Olivos, Gallagher, & Aguilar, 2010). “Helping families receive the necessary training to manage existing resources or to acquire needed resources should be considered if family-focused interventions are expected to yield greater benefits than traditional child-oriented approaches” (Smith et al., 2001, p. 260). Understanding the needs of hearing families of a child with a hearing loss is of key importance for helping establish family-centered approaches to facilitating interventions and providing resources.

Hearing Loss

Laterality of Hearing Loss

Hearing loss may be present in one or both ears. A bilateral hearing loss affects both ears, though not necessarily to the same degree. A unilateral hearing loss affects only one ear, with normal hearing in the other ear. A unilateral loss can affect speech reception and processing, especially in the presence of noise. Localization of sounds may also be impacted. Social situations are sometimes difficult, as speech is easily misunderstood when other noise, parallel conversations, playground noise, cafeteria chatter, etc., is present.

Studies of quality of life in children with a unilateral hearing loss found that although barriers to education and communication were experienced, the social functioning score was much different from those students with a bilateral hearing loss or no hearing loss (Borton, Mauze, & Lieu, 2010). A comparison of children with a unilateral hearing loss and children with no hearing loss found that there were significant differences between the two groups in the areas of attention, academics, communication, behavior, and class participation. In addition, no significant difference were found in any of the areas based on the degree of loss or use of amplification within the group with unilateral hearing loss (Most & Tsach, 2010).

Cochlear Implants

Cochlear implantation began in 1972 at the House Ear Institute (Schow & Nerbonne, 2007). As the technology has become much more advanced from the single electrode implant of that time, so has the prevalence of cochlear implants in babies and children. A data study of new cochlear implants in 2001 indicated that the largest number of new implantations occurred in children under the age of 6 and the second largest number occurred in children ages 6-17 (National Institutes of Health, 2013). Candidacy guidelines for cochlear implants in children under the age of 18 require a moderate to profound loss in the low frequencies or a severe to profound loss in the mid to high frequencies, a specific percentage on aided speech recognition for both ears, and parents who are on board for a full schedule of auditory training (Schow & Nerbonne, 2007).

While studies have revealed differences between the laterality of hearing loss, the presence of a bilateral cochlear implants does not necessarily aid in binaural hearing for children when measured by localization tasks (Van Deun et al., 2010). A study of the quality of life of children with cochlear implants as perceived by the 21 children and their parents revealed that parents felt their children gained a mean score of 3.8 on a 5 point scale of benefit in areas including sense of self, vocabulary and speech perception/production, as well as relationships with the family (Chmiel, Sutton, &

Jenkins, 2000). Asberg, Vogel, and Bowers (2007) indicated that one aspect of lower stress in parents of children with cochlear implants could be the ability of the child and family to communicate effectively.

Statistics in South Carolina

The prevalence of deafness in the United States is less than one in 1,000 people before the age of 18. When looking at “functional deafness,” the incidence increases to two to four of every 1,000 people, with more than half of those cases being attributed to individuals over the age of 64. When adding a severe hearing loss to the definition, the number increases significantly, indicating that 9-22 of every 1,000 people are included in this category. Again, more than 50% of those are over the age of 64. If further breaking down the statistics by age group, those less than eight years old contributed no data to the census. Individuals ages 8-17 comprise .07% of the deaf population and .57% of the hard of hearing population (Mitchell, 2005). One out of every 2,000 children in the United States is born with a hearing loss of 41 decibels or greater. Within the Southern region of the United States, 92.5% of deaf and hard of hearing children come from hearing mothers and 86.1% from hearing fathers. In addition, the unknown hearing status of mothers represents .5% and fathers 8.5% (Gallaudet Research Institute, 2001).

Within the state of South Carolina, 101,896 students are served for some form of disability within school districts, state operated programs, or Head Start programs. Of these, 1,121 are categorized Deaf and Hard of Hearing as a primary disability. Children ages three to five comprise of 100 of these 1,121 students, while the remaining 1,021 consist of individuals ages 6-21 (South Carolina Department of Education, 2008). While there is no specific locatable information regarding the number of children in the state of South Carolina with cochlear implants, a study conducted by Bradham and Jones (2008) estimated the number of candidates for a childhood cochlear implant in the United States as 12,816 with 175 of those being in the state of South Carolina. However, candidacy does not mean the child received the implant.

Educational Placement/Process in South Carolina

Educational placements for students receiving special education services in the state of South Carolina cover a range of environments. For students ages three through five, about 58% are in a regular early childhood program at least 80% of the time. Thirteen percent are in a regular early childhood program less than 40% of the time and 5% are in a regular early childhood program 40-79% of the time. Approximately 12% are in a separate class. Less than 1% are educated at home or in a separate school. Early intervention services in the state of South Carolina start at birth and continue through the age of five. At the time a student turns six, early intervention and preschool placement, which begins at age three, is changed to regular school age placement. Student placement for those ages 6-21 indicates approximately 57% are inside a regular class 80% or more of the day, 20% inside a regular class 40-79% of the day, and 20% inside a regular class for less than 40% of the day. Less than 1% of students are in separate schools, residential facilities, home-based, on medical homebound, in correctional facilities, or parentally placed in private schools (South Carolina Department of Education, 2008).

A variety of outreach services are available within the state. Agencies like the University of South Carolina Speech and Hearing Center and the Medical University of

South Carolina offer speech and hearing services, a cochlear implant program, auditory-verbal therapy, articulation training, and augmentative communication devices. The Department of Mental Health Deaf Services offers mental health services to deaf and hard of hearing individuals and their families as well as videos, training, and presentations to the community. The South Carolina Association of the Deaf offers education, advocacy, support and resources to deaf and hard of hearing individuals, families, and professionals who work with the population. The South Carolina School for the Deaf and Blind Outreach Services and South Carolina Department of Health and Environmental Control BabyNet programs provide early intervention services for deaf and hard of hearing infants and toddlers ages birth through 3, itinerant teachers, sensory information, sign language interpreters, workshops for parents and service providers, summer programs, and equipment distribution for a variety of electronic devices including TTYs, videophones, and bed shaker alarms. First Sound provides newborn hearing screenings and early detection intervention programs. Beginnings of South Carolina provides a plethora of resources and direction to parents of deaf and hard of hearing children across the state.

Parental Stress and Hearing Loss

Parenting a child with a hearing loss can impact daily life and family functioning. A study of 36 hearing mothers of deaf children found that a greater hearing loss, higher life stress, and lower supports caused poorer overall personal adjustment (Calderon & Greenberg, 1999). Often the diagnosis is the first time the parent has been exposed to hearing loss. A study of 45 parents and caregivers found that for all but 2 individuals, the deaf child was the first experience with deafness (Young & Tattersall, 2007). Understanding how a childhood hearing loss affects hearing parents is vital to providing appropriate services to both the child and the family.

Stress and Deafness

Parents of children with a hearing loss report greater stress when children are unable to communicate orally and/or they themselves are unable to communicate effectively via sign language (Pipp-Siegel et al., 2002; Sardar & Kadir, 2012; Zaidman-Zait, 2008). Hintermair (2000a) compared parents of children with a hearing loss with parents of children with a hearing loss and additional disabilities and found that while stress was higher in the child domain for the additional disabilities group, there was an insignificant trend toward greater stress in the parent domain. "Parenting a deaf child can make some of the common parenting demands more challenging, thereby establishing a completely new set of unique, daily demands" (Zaidman-Zait, 2008, p. 140). Asberg, Vogel, and Bowers (2008) found similar stress levels in parents of children with and without hearing loss.

A study of 21 parents and grandparents of a child with a hearing loss revealed initial feelings of helplessness and confusion in response to the diagnosis (Nybo et al., 1998). Common themes derived from a qualitative investigation of parents, grandparents, and educational staff included parental struggle with the diagnosis, grief, communication issues, and dealing with system hurdles when trying to attain services (Freeman et al., 2002). A study of 28 families of children with hearing loss discovered that 64% of mothers and 70% of the fathers spent a significant amount of time dealing with the hearing loss and that 28% of parents relocated their homes to be closer to services (Calderon, Bargones, & Sidman, 1998). Communication within the family and with others is of key importance to developing higher competencies and lowering overall stress.

Communication Stress and Deafness

Hearing parents of children with a hearing loss, depending on degree of loss, are forced to confront the differences between themselves and their child, especially in the area of communication (Koester et al., 2008; Sardar & Kadir, 2012). Deaf children of hearing parents experience a significant impact on communication development, which, in turn, affects academic and social development (Calderon & Greenberg, 2008; Marschark, 1993). The social and mental development of the child is also impacted by a hearing loss, as it affected peer relations and communication within the school setting (Fellinger et al., 2009).

A study of 120 parents of deaf children found no significant difference in the functionality of families of children who are deaf and families of children who are hearing (Fisiloglu & Fisiloglu, 1996). Differences in communication are noted between hearing and deaf parents of children with hearing loss (Loots et al., 2005; Mitchell & Karchmer, 2005). Family conversational styles have been found to affect deaf children's level of participation (Bodner-Johnson, 1991). Stobbart and Alant (2008) proposed that the needs and experiences of hearing parents needs to be investigated further, as hearing parents experience language barriers with their own children. Language can simultaneously be a defining source of pride within a group and a focus for stigma from those outside the group (Meadow, 1975). This is why the correlation between relationships and deafness becomes another important aspect of investigation.

Relationship Stress and Deafness

When circumstances are present that alter the development of either side of the parent-child relationship or disturbs the normal flow of social exchange between the two, the relationship can be negatively impacted (Koester et al., 2008; Sardar & Kadir, 2012). Most research showed that interactions between hearing parents and children with hearing loss were less than ideal (Pipp-Siegel, 1998). A study of parents of 77 children with a severe-profound hearing loss found that over time, all members of the family believed they grew closer together (Nybo et al., 1998). An informal qualitative survey of hearing parents' perceptions of grandparental support at time of diagnosis and time of survey found that 60% reported no change, 30% believed support had improved, and only 10% felt the level of support had become worse (Moores, Jatho, & Dunn, 2001). Within family systems, parents felt judged by choices and decisions about amplification they made for their children (Jackson, Traub, & Turnbull, 2008).

Relationships with service providers was found to be the most frequently cited resource for collaborative problem solving by parents of children with cochlear implants, while the relationships with other parents of children with a hearing loss were identified as providing emotional validation (Zaidman-Zait, 2008). Agencies providing services for children with hearing loss and their families cite family acceptance of the diagnosis and difficulty reaching parents as significant threats to service provision (Bradham, Houston, Guignard, & Hoffman, 2011). Hintermair (2000b) reported that having a social network provided parents with less isolation, more acceptance of the child, and improved interactions. In addition, contact with a deaf adult lowered depression and isolation (Hintermair, 2000b). Another study found the introduction of a deaf mentor into the support system increased expressive and receptive language and decreased parental frustration (Watkins, Pittman, & Walden, 1998). Relationships with parents and parental involvement was found to be one of the greatest threats to programs designed to assist in the early detection and intervention of childhood hearing loss (Bradham et al., 2011).

Significance

A greater understanding of parental stress may help facilitate parental competence and satisfaction, factors which directly affect quality of parental stress, parent-child relationships, and family functioning (Zaidman-Zait, 2008). The impact of communication on social, academic, and emotional development of children with hearing loss cannot be overstated (Calderon & Greenberg, 2008; Marschark, 1993). Families who receive appropriate support services report better quality of life (Moores et al., 2001). A few studies indicate that parental stress increases due to communication issues between a child with hearing loss and a hearing parent (Loots et al., 2005; Pipp-Siegel et al., 2002; Sardar & Kadir, 2012; Zaidman-Zait, 2008), Several studies have examined the way parents feel they and their families and friends respond to their choices for and the needs of the child with hearing loss (Calderon et al., 1998; Fellinger et al., 2009; Freeman et al., 2002; Jackson et al., 2008; Koester et al., 2008; Nybo et al., 1998). Research focusing on the influence a childhood hearing loss has on the stress of hearing parents within the framework of family systems theory is needed to effect positive social change. The results of this study provide valuable insight that educators and service providers can use to directly benefit parents and families of children with hearing loss.

Participants

Hearing Parents of Deaf Children

The prevalence of deafness in children prior to age 18 is one in every 1,000 (Mitchell, 2005). One of every 2000 children born in the United States has a moderate or greater hearing loss (Gallaudet Research Institute, 2001). More than 90% of children born with or who acquire a hearing loss are born to hearing parents (Marschark, 1997; Marschark & Wauters, 2008). The introduction of a child with a hearing loss into a hearing family has been shown to extract strong feelings of guilt, anger, sorrow, and confusion, sometimes precipitating a crisis (Calderon & Greenberg, 2008; Koester & Meadow-Orlans, 1990). A child with hearing loss can affect parental confidence, familial communication, and make differences between the parent and child more blatant (Koester et al., 2008).

Some parents have translated behaviors associated with a hearing loss with stubbornness, inattention, or delays. More often than not, these behaviors are not attributable to the hearing loss itself, but the development of the child within the family (Mertens, Sass-Lehrer, & Scott-Olson, 2008). A case study done on hearing parents of a deaf child revealed that professionals did not spend time determining the feelings and needs of the family, which could have helped with adapting to and making decisions about their child's hearing loss (Spencer, 2008).

Methodology

Status of Research on the Continuum

Research into support for families of children with a disability using Systems Theory as a theoretical framework includes studies that focused on well-being, resources, socioeconomic status, interventions, extended families, and siblings (Britner, Morog, Pianta, & Marvin, 2003; Canary, 2008a; D'Arcy, Flynn, McCarthy, O'Connor, & Tierney, 2005; Keen & Knox, 2004; Taylor et al., 2005). No studies examining hearing loss and systems theory were found. Studies on the impact a childhood hearing loss has on the family generally focus on one area of impact, but not all three areas of stress, communication, and relationships.

Response to Current Research

This study addressed a gap in the literature more than 20 years old. The survey used was modified from its original use as part of a larger mixed-methods study conducted in 1990. The quantitative survey design of this study was chosen to replicate a portion of the previous study in a location not previously represented. In addition, given the number of possible participants and geographic location, the population being surveyed was better reached using quantitative methods in a survey format.

Summary

A childhood disability can impact family life in a multitude of ways. The disability may have a negative impact of family functioning (Epley, Summers, et al., 2010). Parental stress, communication issues, and relationships within and outside of the family unit may inversely influence the child's limitations (Dempsey et al., 2009; Epley, Summers, et al., 2010; Tomasello et al., 2010).

The review of literature on parental stress, communicative stress, and relationship stress was comprised primarily of studies conducted with disabilities other than a hearing loss. Because there is limited research on this topic within the population chosen for this study, it was of significant importance to investigate the impact other disabilities have on families, so similarities and differences could be identified.

Chapter 3: Research Method

Introduction

In this research study, I used a quantitative research approach to scrutinize the stress of hearing parents across three types of childhood hearing loss: unilateral, bilateral, or the presence of a cochlear implant(s). I a review of the literature, I determined that there was a need for research focusing on the influence a childhood hearing loss has on the stress of hearing parents, specifically within the framework of family systems theory. The purpose of this research study was to examine whether the stress of hearing families differed by the type of their child's hearing loss: unilateral, bilateral, or the presence of a cochlear implant. Incorporating a convenience sample, a 24-item questionnaire was used to collect anonymous data from hearing parents of children with a hearing loss receiving services in the state of South Carolina. An exploratory factor analysis was conducted to determine which factors accounted for the variance in responses. ANOVA procedures were used to identify differences between the three groups. In Chapter 3, I introduce the research design, setting, sample, survey instrument, data collection procedures, analysis methods, and protection of participants for this study.

Research Design and Approach

I chose quantitative research as the design for this particular study, as I sought to determine, through statistical analysis, if the independent variables of laterality (unilateral or bilateral) of a child's hearing loss or presence of a cochlear implant(s) influenced the dependent variable of parental stress. Quantitative research is defined as "explaining phenomena by collecting numerical data that are analyzed using mathematically based methods, in particular, statistics" (Muijs, 2004, p. 1). The advantages of quantitative research include filtering out external factors to generate unbiased results, proving or disproving a hypothesis with statistical information, stronger confidence than qualitative measures, and benefits in measurement (Denscombe, 2010; Muijs, 2004). Disadvantages can include the quality of data collected, which can be controlled by questions asked, the fact that some studies are not as scientifically objective as they may appear, and the proving or disproving of a hypothesis with little room for gray area (Denscombe, 2010; Muijs, 2004).

The design approach for this study was survey research using factor analysis, descriptive statistics, and ANOVA procedures. Survey research is used to "describe, compare, or explain individual and societal knowledge, feelings, values, preferences, and behavior" (Fink, 2006, p. 1). The use of a convenience sample, not a random sample, eliminated the use of a true experimental design. Because individual responses were divided into three comparison groups (unilateral hearing loss, bilateral hearing loss, presence of cochlear implant[s]) and then compared, a quasi-experimental design was considered; however, the lack of a control group or treatment group calls for a nonexperimental design (Creswell, 2003). As the researcher, I was known in some areas of the small population; therefore, anonymity was developed to reduce the possibility of influencing responses. Given the anonymous nature of the survey, qualitative follow-up interviews were not possible, thus causing a mixed-methods approach to be rejected. The anonymity of reporting also helped limit researcher interference.

This study was noncausal in nature because multiple factors may influence parental stress at any one given moment in time. In this study, I sought only to determine if there were differences for the dependent variables of parental stress, communication stress, and relationship stress based on the independent variable of childhood hearing loss. I was not trying to prove cause of parental stress, just determine if a relationship existed between the variables.

The majority of research on parental relationships with deaf children involves only those with deaf parents. Most research conducted with hearing parents of deaf children falls in the qualitative paradigm. Given this, more research in the quantitative paradigm was warranted, specifically within the correlational and non-experimental domains.

Population

The population for this study was hearing parents/guardians over the age of 18 who had at least one child with a hearing loss between the ages of birth and 21. The parents and/or child must have been participating in or receiving services from agencies, early intervention programs, or educational programs within the state of South Carolina. There were approximately 1,100 students enrolled in these programs across the state (South Carolina Department of Education2008).

The size of the population was the parents/guardians of approximately 1,100 children enrolled in programs across the state. Because 90 % of these children are born to hearing parents, the potential sample size for this study was 990. The projected sample size was 138, given an alpha of 0.05, power at 0.95 and a medium effect size at 0.15 (explained in more detail in the Sample Size section).

Sampling and Sampling Procedures

Sample Method

A multistage sampling design, or clustering design, was used, as the population was not accessed directly by the researcher, but through groups and organizations who disseminated a link to the online survey (Creswell, 2003). A convenience sample was used, drawn from the population of hearing parents of students meeting the above criteria. Stratification of the population did not take place prior to the selection of the sample, as the degree and loss of children with a hearing loss within the state are not known factors and could not be predicted. A random sample would provide each member of the population an equal probability of being selected, allowing for greater generalizability of the results (Creswell, 2003). Even though the State Department of Education identifies the approximate number of students with hearing loss in the educational system, personally identifiable information is considered private and inaccessible to the public. Therefore, obtaining a random sample was not plausible for this study. Given the nonprobability sampling measure used in this study, the results may not provide a full representation of the population sampled (Creswell, 2003).

Sample Size

Given that 90 % of children with a hearing loss are born to hearing parents, and the sample for this study was the hearing parents of children with hearing loss receiving educational services in the state of South Carolina, the potential sample size for this study was 990. There were approximately 1,100 students receiving educational or early intervention services within the state of South Carolina. Ninety percent of this population is 990. This potential sample size of 990 hearing parents of a child with a hearing loss was identified through educational and early intervention programs serving the students within the state. The level of significance for this study that was used throughout was the alpha = 0.05 or a confidence level of 95 %, the most commonly used level of significance (Noymer, 2008). The effect size calculation helped determine the necessary sample size for this study.

Using G Power 3 Statistical Software, a priori analysis for a linear regression analysis was run in order to determine the effect size. An analysis was run with the alpha at 0.05, power at 0.95, and a medium effect size at 0.15. The analysis indicated a minimum sample size of 138 subjects. This number of subjects supports the required number for an EFA following the Rule of 100 (Gorsuch, 1983; Kline, 1979) and the Rule of Five (subjects to variables; (Arrindell & van der Ende, 1985; Gorsuch, 1983; Hatcher, 1994). The Rule of 100 indicates that a minimum of 100 subjects is required to run an EFA. The Rule of Five requires five subjects per item on a scale. For this study, the survey has 24 items, so a minimum of 120 subjects would be required following the Rule of Five.

Procedures for Recruitment, Participation, and Data Collection

Recruiting Procedures and Data Collection

The recruiting procedures for this study occurred through educational and early intervention programs providing services to children through age 21 with a hearing loss living and receiving services in the state of South Carolina. The online link to the survey was made available on one agency website and in newsletters that were delivered to service providers and parents of children with a variety of disabilities including but not limited to hearing loss. The only demographic information collected from participants were the cochlear implant status and the laterality of their child's hearing loss, the child's age, and verification that they were (a) a hearing parent at least 18-years-old with at least one child with a hearing loss who was (b) 21 years of age or younger living and receiving services within the state of South Carolina.

Online surveys were submitted via the survey site housed at Survey Monkey (surveymonkey.com). Surveys took, on average, 10 minutes to complete. No special exit counseling or debriefing procedures were required for this study. There were no follow-up procedures to put in place, as the anonymity of the survey limited the knowledge of who had or had not completed the survey.

Eligibility Criteria for Participants

Participants were selected on their hearing status and that of their child who was receiving educational or early intervention services within the state of South Carolina. The parents must have been 18 years of age and of hearing status with at least one child with a hearing loss. Those parents who had a hearing loss were not eligible for participation in the study. No limitations were placed on gender or ethnicity, as this is an anonymous study and this data was not collected.

Informed Consent

Informed consent was provided online prior to the survey questions. This notice clearly stated that once submitted, the anonymity of the study prevented withdrawal from the study. The informed consent included an invitation statement, background information, criteria for participants, procedures, sample questions, a statement of the voluntary nature of the study, compensation information, privacy information, and contacts for assistance at both the university and local levels.

Pilot Study

Conducting a pilot study is a crucial step to improve internal validity of a questionnaire, identify potential problems with the proposed instrument and methods, and ensure the researcher works out any potential issues prior to the large-scale study (Johnson & Christensen, 2004). In July of 2013, I conducted a small-scale pilot study to ensure the adaptations made to the original questionnaire format did not negatively impact the reliability or validity of the instrument. I have outlined findings from the pilot study and subsequent changes to the main study in Chapter 4.

"Influence of Childhood Hearing Loss on Hearing Parents" Questionnaire

The original questionnaire, "Impact of Childhood Hearing Loss on the Family," was designed by Meadow-Orlans and Lytle as part of a larger mixed methods research study to better understand the backgrounds of students entering the Model Secondary School for the Deaf (MSSD) (Meadow-Orlans, 1990). The questionnaire was created using a framework of analysis of interviews of parents of deaf children conducted by the developers of the instrument as well as several other researchers focusing on deafness and its impact on the family (Meadow-Orlans, 1990). The following five areas of general concern were gleaned from a review of the research: the impact on family members, communication concerns, relationships within the family and with service providers, parental satisfaction with the progress of the child, and the way the child is treated by others. The questionnaire was developed using a true/false format, forcing a choice for items and limiting ambiguity for the factor analysis that would follow (Meadow-Orlans, 1990). Revisions were based on comments and questions from the initial sample of 100 parents, though an exact number of returned surveys was not disclosed.

The final questionnaire items were selected based on comments from the second revision, an analysis of nonresponses, and an analysis of the responses received (Meadow-Orlans, 1990). Three scales of eight questions were constructed from the possible 39 items. The three scales are categorized as family stress, communication, and relationships with professionals and others outside the home (Meadow-Orlans, 1990). These remaining items resulted in the 24-item questionnaire that was adapted for use with this survey.

Adaptation of the Instrument

The questionnaire contained dated vocabulary including use of the term "hearing impaired," which points to a medical model of deafness. The original questionnaire used a four-point Likert scale with no midpoint or neutral option. The original questionnaire also placed the most positive response as the far right choice instead of providing consistent choices for each item left to right. Permission was obtained from Gallaudet University Press (Appendix A) to use and adapt the questionnaire to include the updated vernacular of “deaf or hard of hearing” in place of “hearing impaired.” In addition, the survey was modified to incorporate a five-point Likert scale with a midpoint/neutral option and consistent disagree to agree responses for each item. When analyzing the data, some questionnaire items will need to be placed into reverse ordinal ranking because of this, however, it will serve to reduce error and influence of answers. The original instrument was created as a part of a much larger project that collected additional demographic information and included qualitative follow-up interviews. The demographic questions were reduced and altered to meet the needs of the proposed study and follow-up interviews were eliminated to maintain anonymity. In addition, the name of the questionnaire was changed from “Impact of a Childhood Hearing Loss on Family” to “Influence of Childhood Hearing Loss on Hearing Parents” to align with the nature of the proposed study.

Reliability

The original study analyzed factor loadings for each question. Reliability was determined using Cronbach’s alpha. The Chronbach’s alpha for factors of general stress was .74. For factors of communication, Cronbach’s alpha was .75. Cronbach’s alpha for factors of relationships was .71. A general rule for reliability using Cronbach’s alpha is a score of .70 and above. Results of the pilot study indicated Cronbach’s alpha scores of .83, .81, and .80 for general parental stress, communicative stress, and relationship stress respectively.

Materials

The materials needed to conduct this study included securing an online host for the web-based survey. I used Survey Monkey (surveymonkey.com), which required payment, as the instrument contained more than the limited number of questions and required more than the limited number of responses granted to a free account. E-mail and phone connections were important assets, as communication with state agencies and programs was of essential.

Data Collection

Prior to collecting any data, I submitted an IRB application and all supporting documentation to Walden University's Institutional Review Board, in order to ensure the safety of the study's participants. The IRB application included research questions, data collection tool, description of participants, potential risks and benefits of the study, how the data would be kept confidential, and procedures for informed consent. Once approval was received from Walden University's Institutional Review Board, the researcher utilized Survey Monkey, a website that houses online data collection surveys, to create the online informed consent, data collection instrument, link for participants to request a copy of the results, and a unique online URL for the survey.

A two-step process was used to administer the survey. A first e-mail was a short advance notice to statewide organizations and programs serving deaf and hard of hearing children and their families as well as educational and early intervention providers. Seven business days later, an e-mail containing the URL for the survey and an invitation to participate were sent to the same organizations and programs. These organizations and programs distributed the e-mail invitations to hearing parents of children with a hearing loss. A link to the survey was posted on one organization’s website. The link to the survey was also sent home in printed newsletters, flyers, and via other methods of information dissemination as determined by each organization.

Data Analysis

The data analysis was conducted using the SPSS statistical software. Data were analyzed using descriptive and inferential statistics. Specifics for each section follow.

Research Question

The specific research question for this study was

1. What relationship existed among the independent variables of a unilateral childhood hearing loss, a bilateral childhood hearing loss, and a child with a cochlear implant(s) and the dependent variables of parental stress, communicative stress, and relationship stress?

Hypotheses

$H_1$1 There was a difference in stress levels amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_1$2: There was a difference in communicative stress amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_1$3: There was a difference in relationship stress amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_1$4: There was a difference in total instrument scores amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

Null Hypotheses

$H_0$1: There was no difference in stress levels of hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_0$2: There was no difference in communicative stress levels of hearing parents among unilateral, bilateral, and cochlear implant groups..

$H_0$3: There was no difference in relationship stress levels of hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_0$4: There was no difference in total instrument scores of hearing parents among unilateral, bilateral, and cochlear implant groups.

Factor Analysis

Exploratory factor analyses were conducted to determine which factors were loading on each other and which factors accounted for the largest variance. One- and three-factor solutions were run to determine which questions truly fit into their intended categories. Results from the one-factor EFA were used to create scores that were subsequently used in the ANOVA procedures.

Descriptive Statistics

This section of analysis included means and standard deviations for all three subsets of stress and three types of hearing loss. Descriptive statistics "provide a powerful summary that enables comparisons across people or other units" (Trochim & Donnelly, 2007, p. 265). This method of analyzing data enabled me to examine the data quantitatively and identify patterns that emerged. SPSS software was used to conduct these analyses. In addition to this analysis, correlation and ANOVA tests were performed to identify relationships between the independent and dependent variables.

Analysis of Variance

One-way ANOVA tests were run to determine significance between total scores for the groups. Tests were run using both observed total instrument scores and latent total instrument scores. Significance was set at $p = < .05$. Post-Hoc Tukey procedures were run for both observed and latent scores to determine relationships between specific groups.

Limitations and Threats to Validity

Limitations

The limitations of this study included the lack of generalizability of results since only parents from South Carolina were included. While the anonymous nature of the questionnaire may have help combat responder attrition, it was still a possibility given the self-reporting aspect. Because I was known within the deaf community and educational realm, social desirability and acquiescence bias were possible, though both should have been reduced by the anonymity of the survey. Incomplete surveys also further limited this study. In addition, there was very little research on childhood hearing loss and hearing parental stress for comparison.

Threats to Validity

Threats to instrumentation validity were reduced because a pilot study was conducted. However, the sample size for the pilot was significantly low, and an EFA was unable to be conducted. Therefore, an EFA was run prior to any additional analyses for the larger study. Limiting the population for this study to hearing parents of children 0-21 with a hearing loss within the state of South Carolina reduced the generalizability of the results, thereby limiting population validity.

Ethical Procedures

Protection of Human Participants and Collected Data

The questionnaire was anonymous, thereby protecting the identity of the participants and eliminating the need for confidentiality of responses. No unintended disclosure of confidential information was foreseen, as the study contained no open-ended questions and did not specifically ask for any protected information. No irrelevant personal information was sought. There was no concern for intrusion or observation in public places because the survey was taken independently and was completely anonymous. The possibility of misunderstanding as a result of experimental deception was limited by the fact that there was no placebo treatment or personal interaction between the researcher and the participants. The questionnaire was disseminated to hearing parents of deaf and hard of hearing children, not to deaf or hard of hearing adults nor any person under the age of 18, thereby eliminating the possibility of interacting with protected groups of individuals. While it is possible that the e-mail with the link to the online survey was provided to deaf or hard of hearing parents of a deaf or hard of hearing child, the informed consent specifically indicated the requirements for inclusion, so by agreeing to the terms of the informed consent, the parents indicated they were of hearing status. Any misinformation was not identifiable, as the survey did not collect information on the hearing status of the parents.

Conducting this study within the researcher’s own field of work could have potentially created an ethical dilemma. This was counteracted by dissemination through programs and websites and the anonymity of the study. It was an assumption of the study that the anonymous nature of the survey eliminated any undue influence on participant responses. Anonymous data was kept in a fireproof lock box in my home, on my hard drive, and stored on a flash drive kept in the fireproof lock box, and will remain there for five years. At the end of five years time, I will shred the hard copies and erase the information from the hard drive and the flash drive.

Dissemination of Findings

Results of the study were provided to Gallaudet University as part of the agreement to use and adapt the previously developed questionnaire as part of the current study. Findings were also provided to Beginnings of South Carolina, a non-profit organization for parents of children who are deaf and hard of hearing, to be used as data for grant writing and project development. A summary of findings was e-mailed to parents who, upon completion of the survey, indicated via a separate link that they would like a copy sent to them via e-mail. In addition, I will seek publication of an article in a peer-reviewed journal related to deafness and deaf studies upon completion of the doctoral program.

Summary

This chapter provided the methodology that this study employed. The research design and rationale were introduced. The research question and hypotheses were presented. The population, setting, and sample for the study were reviewed including eligibility criteria for participants. The previously constructed “Impact of Childhood Hearing Loss on Family” questionnaire was identified and described, as well as the adaptations that were made to meet the needs of this study. A data collection plan was outlined and data analysis procedures to include descriptive statistics, correlation, and ANOVA analyses were explained. Ethical procedures and dissemination of findings were also addressed. The results of this study are presented in Chapter 4.

Chapter 4: Results

Introduction

In this chapter, I will explain the process for and the results of the pilot study mentioned in Chapter 3, describe the data collection techniques for the main study, present discrepancies between what was planned in Chapter 3 and what was actually done, and report the results of the main study. I sought to determine what relationship, if any, existed between the independent variables of a unilateral childhood hearing loss, a bilateral childhood hearing loss, or a child with a cochlear implant(s) and the dependent variables of parental stress, communicative stress, and relationship stress.

Hypotheses

$H_1$1 There was a difference in stress levels amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_1$2: There was a difference in communicative stress amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_1$3: There was a difference in relationship stress amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_1$4: There was a difference in total instrument scores amongst hearing parents among unilateral, bilateral, and cochlear implant groups.

Null Hypotheses

$H_0$1: There was no difference in stress levels of hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_0$2: There was no difference in communicative stress levels of hearing parents among unilateral, bilateral, and cochlear implant groups..

$H_0$3: There was no difference in relationship stress levels of hearing parents among unilateral, bilateral, and cochlear implant groups.

$H_0$4: There was no difference in total instrument scores of hearing parents among unilateral, bilateral, and cochlear implant groups.

Pilot Study

In July of 2013, I conducted a small-scale pilot to ensure the adaptations made to the original questionnaire format did not negatively affect the reliability or validity of the instrument. The pilot study was conducted after seeking and receiving approval from Walden University's IRB. The approval number was 05-14-13-0093516 (see Appendix B). After meeting with the director of a local nonprofit organization specializing in providing outreach to families of children with hearing loss, I provided envelopes, copies of the questionnaire, stamps, and labels for mailing to hearing parents who were clients. The organization handled addressing and mailing packets to parents. Anonymity of the participants was ensured because only the agency had access to their own client list.

Of the 42 surveys disseminated, 21 were returned. Only 20 surveys were complete and used in statistical analyses. To replicate the tests of reliability conducted with the original instrument, statistical methods for Cronbach's alpha, a factor analysis, and descriptive statistics were processed. The 24 items were separated into the three constructs of parental stress, communicative stress, and relationship stress with eight questions in each construct. Because the questionnaire was altered to prevent the most positive choice from being on the far right and aligned so all options were identical across for each question, Item Numbers 2, 5, 6, 9, 13, 18, and 20 were entered into SPSS with reverse coding.

Descriptive Statistics: Pilot Study

The initial plan for this study was to examine the influence of both the degree (mild, moderate, moderate-severe, severe, profound, or cochlear implant) and laterality (unilateral or bilateral) of a childhood hearing loss on the stress levels of parents. However, a look at the frequencies for degrees of hearing loss for the right and left ears indicated the need to revise the study. Previously, the proposed groupings for the degree and laterality of hearing loss were as follows in Figure 1:

Unilateral Mild	Bilateral Mild
Unilateral Moderate	Bilateral Moderate
Unilateral Moderate-Severe	Bilateral Moderate-Severe
Unilateral Severe	Bilateral Severe
Unilateral Profound	Bilateral Profound
Unilateral Cochlear Implant	Bilateral Cochlear Implant

Figure 1. Initially proposed groupings for degree and laterality of hearing loss

Upon examining the frequencies, it was determined that it was not feasible to group in this manner. The problem lies in the fact that only one of the respondents reported the same degree of loss bilaterally. The rest had one degree of loss or a cochlear implant on one side and a different degree of loss or a cochlear implant on the other side (see Table 1).

Table 1

Frequencies for Degree of Loss by Side: Pilot Study

Degree of Loss	Right Ear Frequency	Left Ear Frequency
Mild	1	2
Moderate	2	3
Moderate-Severe	2	1
Severe	1	2
Profound	6	3
Cochlear Implant	8	9

The number of groups this could potentially create would complicate the study beyond what could be completed in a reasonable amount of time or with the population size his study aimed to reach. The proposal to alter the study from degree and laterality of hearing loss to examine only the laterality by grouping into three categories of unilateral, bilateral, and cochlear implant(s) was approved by the committee.

The frequencies and descriptive statistics were run in two ways from this point forward: as a whole group (n = 20) and in the split groups of bilateral hearing loss (n=10) and cochlear implant(s; n = 10). No participants reported a unilateral hearing loss. The highest total possible score for the survey was 120. The lowest was 24. The means and standard deviations for total scores are reported in Table 2.

Table 2

Total Instrument Score: Means and Standard Deviations: Pilot Study

	Sample Size (*n*)	Mean (*m*)	Standard Deviation (*sd*)
Whole Group	20	81.05	14.86
Split Group Laterality			
Bilateral	10	78.80	17.46
Cochlear Implant(s)	10	83.30	12.26

While no participants returned surveys reporting a unilateral hearing loss, this may have been partially a result of the distribution method for the pilot study. The nonprofit that sent the packets out had a limited number of clients at that point and reported to have a low number of clients with a unilateral hearing loss. There were no foreseen issues obtaining enough responses for all three categories for the large study.

Reliability and Correlations: Pilot Study

Cronbach’s alpha for the full 24 items was obtained at .856. Cronbach’s alpha was also conducted for each construct. These separate calculations are contained in Table 3.

Table 3

Reliability Analysis of Pilot Study Data

Construct	Number of Items	Cronbach’s Alpha
Full Survey	24	.856
Parental Stress	8	.827
Communication Stress	8	.806
Relationship Stress	8	.793

Since various features of the scale were altered, an exploratory factor analysis was conducted with all 24 items from the large-group sample (*n* = 20) to determine if the items fit the three-factor solution that was found during the creation of the original scale (Meadow-Orlans, 1990). An adequate factor analysis was not possible due to the small number of subjects. Because of this, I examined the correlations of each item in the three subsets of stress. Some items noted significance levels at the .01 and .05 levels, despite being in different categories (see Tables 4, 5, and 6).

Table 4

Correlation Matrix: Pilot Study – Parental Stress Items

		Parental Stress							
	item	**1**	**2**	**6**	**7**	**14**	**16**	**19**	**22**
Parental Stress	**1**	1							
	2	.421	1						
	6	.382	.266	1					
	7	.375	-.066	.129	1				
	14	.600**	.133	.540*	.326	1			
	16	.581**	.182	.167	.541*	.667**	1		
	19	.287	-.040	.230	.439	.604**	.440	1	
	22	.626**	.440	.524*	.390	.500*	.447*	.503	1
Comm. Stress	**4**	.506*	.274	.489*	.388	.562**	.257	.549*	.571**
	5	-.045	.129	.184	-.314	-.004	-.253	-.260	.152
	8	-.234	-.182	.078	-.176	-.013	-.074	-1.73	.036
	10	.456*	.234	.375	.079	.225	-.066	.029	.447*
	11	-.057	-.264	.349	.127	.237	.049	.243	.265
	17	.476*	.080	.329	.062	.450*	.290	.066	.137
	20	.216	.147	.752**	.016	.475*	.015	.098	.239
	23	.323	.224	.602**	-.014	.368	-.058	-.105	.367
Relationship Stress	**3**	-.102	-.208	.116	-.049	.067	-.047	.005	-.231
	9	.247	.273	.499	.116	.293	.160	.381	.426
	12	.080	-.067	.417	.106	.027	-.096	.069	.332
	13	-.042	.000	.037	-.213	-.043	-.124	-.113	-.046
	15	.229	-.298	.169	-.148	.110	-.008	.117	-.068
	18	-.018	-.078	.398	-.295	.183	-.225	-.061	-.102
	21	.178	-.121	.602**	-.084	.267	-.176	.063	.211
	24	.179	.077	.367	.091	.284	.265	.169	.036

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Table 5

Correlation Matrix: Pilot Study – Communication Stress Items

		Communication Stress							
	Item	**4**	5	8	**10**	**11**	**17**	**20**	**23**
Comm. Stress	**4**	1							
	5	-.092	1						
	8	-.260	.487*	1					
	10	.369	.338	.381	1				
	11	.021	.448*	.747**	.415	1			
	17	.287	.219	.234	.550*	.396	1		
	20	.355	.051	.319	.481*	.309	.229	1	
	23	.365	.464*	.333	.462*	.378	.476*	.578**	1
Relationship Stress	**3**	.046	.209	.080	-.203	.091	-.071	.029	-.132
	9	.634**	.177	-.043	.109	.066	.030	.236	.109
	12	.040	.369	.221	.196	.455*	-.069	.131	.067
	13	-.183	.457*	.302	-.192	.199	.124	-.123	.281
	15	.092	.025	-.173	-.042	-.109	-.053	.045	-.227
	18	-.047	.458*	.426	.548*	.493*	.590**	.393	.313
	21	.257	.361	.020	.512*	.369	.364	.405	.317
	24	.187	.080	.151	-.045	.178	-.072	.367	-.039

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Table 6

Correlation Matrix: Pilot Study – Relationship Stress Items

		Relationship Stress							
	Item	**3**	**9**	**12**	**13**	**15**	**18**	**21**	**24**
Relat. Stress	**3**	1							
	9	.592**	1						
	12	.501*	.378	1					
	13	.516*	.299	.311	1				
	15	.667**	.475*	.438	.203	1			
	18	.111	.019	.235	.123	.149	1		
	21	.006	.110	.465*	-.211	.308	.677**	1	
	24	.711**	.622**	.397	.173	.576**	.064	.033	1

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Various cases, including Items 2 and 7 in parental stress, Items 4 and 5 in communication stress, and Items 4, 5, and 8 in relationship stress, were found where items had very low correlations with items in the same subscale and even negative correlations between items in the same subscale. Without the factor analysis, it was difficult to determine if these items hung together and could be scored as a sub score. As a result, an additional reliability analysis was run to determine what Cronbach's alpha would be if each item was deleted. For most of the items that carried negative values in the correlation, the alpha would increase if deleted (see Table 7). Given the negligible difference in alpha and the small size of the sample for this pilot study, none of these items were removed for the main study.

Table 7

Reliability if Item Deleted: Pilot Study

Item	Cronbach's Alpha if Item Deleted	Item	Cronbach's Alpha if Item Deleted
1	.847	13	.857
2	.859	14	.843
3	.857	15	.857
4	.847	16	.856
5	.853	17	.848
6	.837	18	.851
7	.858	19	.854
8	.857	20	.846
9	.845	21	.849
10	.846	22	.846
11	.848	23	.848
12	.849	24	.850

With N of items 24, Cronbach's Alpha is .856

In Table 4, Item 2 had a questionable correlation with Items 7 and 19. When I examined the reliability of the scale with the deletion of Item 2, Cronbach's Alpha increased from .856 to .859. In Table 4, Item 4 had a questionable correlation with Items 5 and 8. If I removed Item 4, the reliability would have decreased to .847. The deletion of Item 8 increased reliability to .857. These increases and decreases were so small that no items were determined necessary to remove for the main study, especially given the small sample size of the pilot study.

Significant correlations between items in the same subsets were expected. Examples of this are Items 1, 14, and 16 in parental stress, Items 8 and 11 and Items 20 and 23 in communication stress, and Items 3, 9, 15, and 24 in relationship stress. Correlations of significance between items in different subsets could prove to be problematic in the larger study. Items 20 and 23 in communication stress and Item 21 in relationship stress showed significance at the 0.01 level with Item 6 in personal stress (See Table 4). Item 17 in communication stress and Item 18 in relationship stress also showed significance at the 0.01 level (See Table 5). While many items in the correlation matrices presented significance at the 0.01 and 0.05 levels, it was not prudent to remove any items with analyses from such a small sized pilot study, nor for such small gains to Cronbach's alpha

Effect Size and Sample Size Calculation: Pilot Study

I used pilot study data to help determine the sample size for the larger study. Because the pilot study returned data from only two of the three potential groups, I ran an independent *t*-test for means, standard deviations, *t*-values, and degrees of freedom. An effect size calculator for Cohen's *d* provided the results listed in Table 8.

Table 8

T-test and Effect Size Calculations: Pilot Study

	Mean	Standard Deviation	*t*	*df*
Bilateral Loss	78.8	17.46	.667	18
Cochlear Implant(s)	83.3	12.26		
Cohen's *d*	Using means and standard deviations	0.29	Using *t* and *df*	0.31

t and *df* assumed equal variances

Cohen's *d* was calculated at 0.30 (the average of Cohen's *d* 0.29 and 0.31 in Table 8). An a priori analysis was initially run with this small effect size. The resulting sample size was 72 subjects. The pilot study only presented findings from two of the three groups. A sample large enough to ensure participants from each of the three hearing loss groups was necessary. Because there is limited research in this area for comparison of effect size, I determined it beneficial to reduce the effect size to 0.15. The smaller effect size means that more participants would need to be evaluated to determine the effect. A larger effect size means less individuals would need to be evaluated to determine the strength of the relationship between hearing loss and parental stress. A generally accepted effect size for psychological studies is small to medium (Burkholder, 2015). Given that limited research exists for this population, using a small effect size to ensure ample representation for each group while not reducing power made for the strongest possibility of reducing Type I and II errors (Rossi, 1990). Using this even smaller effect size, an a priori analysis using G-Power 3 statistical analysis software was run with a power of 0.80

and alpha of 0.05. This resulted in a required minimum of 138 subjects. This sample size would provide for a higher likelihood of collecting enough data to ensure representation from all three hearing loss groups.

Main Study

Data Collection: Main Study

Data collection for the main study took place over an eight-week period from November through January. Proposals to conduct research through both the school for the deaf and one of the local public education districts that serves the deaf and hard of hearing students from several surrounding districts were submitted as a requirement of these two agencies. Concurrently, approval was sought from Walden IRB. Upon receipt of approval from the school for the deaf and the local school district, approval was obtained from Walden IRB, number 10-29-14-00093516 (see Appendix C). I e-mailed an invitation to assist with the distribution of the online survey to all special education directors in the state, the state school for the deaf, and one local and one national nonprofit organization for parents of deaf and hard of hearing children. One week later, I sent an e-mail and flyer of invitation to the same recipients. The e-mail was worded to directly invite hearing parents of deaf and hard of hearing children to participate in the study and indicated that the sending party did not sponsor it in any way. Data collection timeframe began one week later when I received word that the first agency had sent the information to parents.

The initial data collection plan involved using both online and paper versions of the survey. I provided paper flyers with both the online URL for the survey and the e-mail address to contact the researcher with the e-mail invitation for agencies to disseminate. This provided parents with a means of requesting a paper copy of the survey. No parents requested paper copies of the survey and parents submitted all responses via the online data collection site. The national nonprofit organization posted a link to the online survey on their research opportunities section of their website.

While I have no way of knowing exactly how many parents received an invitation via e-mail, flyer, or website posting, the total potential population was calculated at 990. An a priori analysis indicated that a minimum of 138 subjects would be required for this study. At the close of the survey, 172 responses had been submitted. Of these, one refused consent and 20 were incomplete. Because the number of responses was well above the required *n*, removal of these 21 responses occurred making the sample for this study *n* = 151.

Results: Main Study

Descriptive statistics. The frequencies and descriptive statistics were run in two ways from this point forward: as a whole group (*n* = 151) and in the split groups of unilateral hearing loss (*n* = 58), bilateral hearing loss (*n* = 56), and cochlear implant(s) (*n* = 37). The highest total possible score for the survey was 120. The lowest was 24. The means and standard deviations for total scores are in Table 9.

Table 9

Total Instrument Score: Means and Standard Deviations

	Sample Size (n)	Mean (m)	Standard Deviation (sd)
Whole Group	151	62.05	22.58
Split Group			
Unilateral Loss	58	47.52	15.70
Bilateral Loss	56	68.59	21.23
Cochlear Implant(s)	37	74.95	21.63

Factor analyses.

Eigenvalues solution. I ran a principal axis factoring (PAF) with no rotation for eigenvalues greater than one. Table 10 shows the results of this factor analysis. While the results indicate there are four factors with eigenvalues above one, there appears to be only one significant factor with an eigenvalue of 12.79 accounting for 53.28% of the total variance. A scree plot of the analysis (Figure 2) also shows that there is minimal decline between factors two, three, and four in relations with the remaining items.

Table 10

Factor Analysis

Factor	Initial Eigenvalue	% of Variance Explained
1	12.79	53.28
2	1.59	6.61
3	1.17	4.87
4	1.12	4.69
5	.97	4.01
6	.79	3.29
7	.65	2.72
8	.59	2.46
9	.53	2.19
10	.43	1.80
11	.38	1.56
12	.35	1.46
13	.33	1.38
14	.31	1.28
15	.30	1.24
16	.27	1.12
17	.25	1.03
18	.23	.94
19	.22	.90
20	.20	.81
21	.17	.69
22	.16	.67
23	.13	.53
24	.11	.47

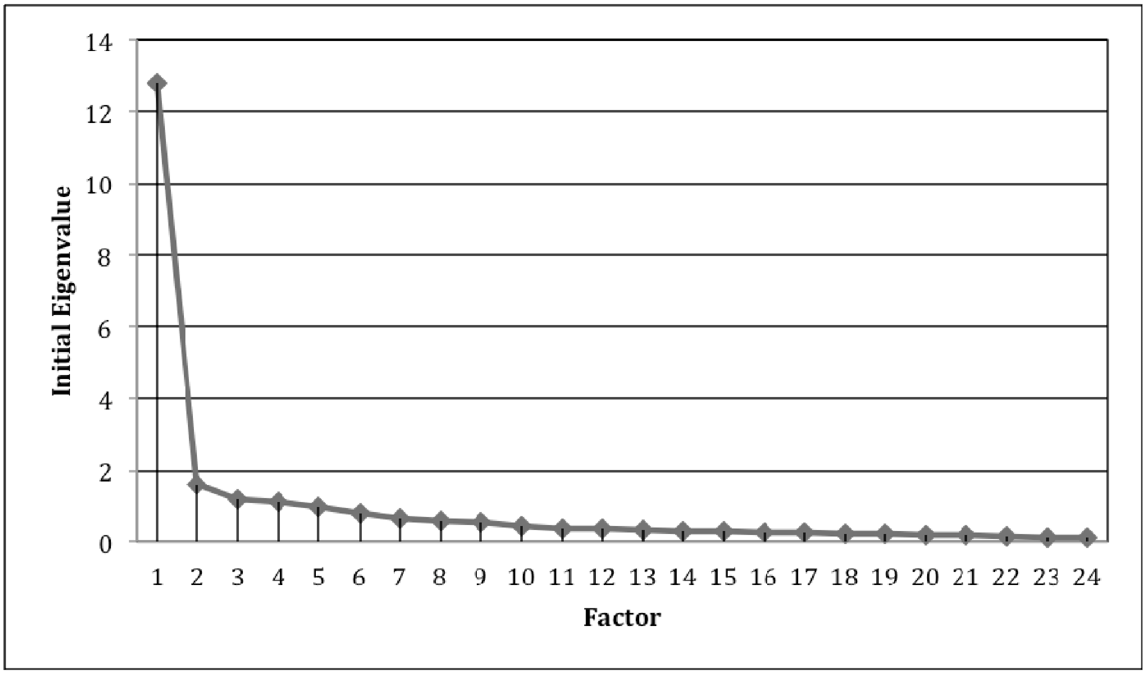

Figure 2. Scree plot for item 2

Three-factor solution. I next ran a PAF for three factors to be extracted with Promax rotation and Kaiser normalization to ensure that the questions fit into the correct categories. I was unable to conduct this analysis in the pilot study given the small sample size. The item/category column of Table 11 lists the question number of the survey as well as the category the original survey intended each item to address. I abbreviated general parental stress as PS, communication stress as C, and relationship stress as R. Results of the three-factor solution indicated that some questions loaded correctly while others cross-loaded or loaded onto other factors.

Table 11

Three-Factor Solution Pattern Matrix

Item		Factor (Category)		
Question Number	Original Category	1 (PS)	2 (C)	3 (R)
16	PS	**.846**	.111	
20	C	.821	.355	-.399
6	R	.768		.116
1	PS	**.722**	-.137	.274
22	PS	**.691**		.100
21	R	.681		.187
9	R	.663		
18	R	.583	-.126	.395
4	PS	**.522**		.373
19	PS	**.517**		.148
7	PS	**.464**		.348
10	PS	**.351**	.281	.221
2	C	.177		
8	C		**.919**	
11	C		**.851**	.124
23	C	.190	**.738**	
17	C		**.692**	.219
5	C		**.645**	
14	C	.233	**.392**	.205
13	PS		.204	.139
15	R			**.858**
24	R		.108	**.761**
3	R			**.726**
12	R		.158	**.587**

Highlighted factor loadings in Table 11 identify questions that loaded as expected into the three categories. Items with loadings above .30 are considered to have the "cleanest factor structure" (Costello & Osborne, 2005). Therefore, those items with a .30 or above were determined appropriately categorized. Those items that do not have a highlighted factor loading, while meeting the .30 requirement for clean factor structure, either cross-loaded or loaded onto a different factor. Some items, like Questions 18 and

20, cross-loaded while also loading higher in a different category. Items 6 and 21 loaded highly in a different category, while not meeting the recommended .30 for their intended category. Questions 2 and 13 did not meet .30 for any category and did not load at all into the intended category. Enough questions loaded correctly into their intended categories to reduce the items used for data analysis. The recommended minimum is three and there were seven items for parental stress, six for communication stress, and four for relationship stress, as highlighted in Table 11 (Costello & Osborne, 2005). Eliminating the questions that did not load as expected, Items 2, 6, 9, 13, 18, 20, and 21 (those not highlighted in Table 11), would have increased the ratio of respondents to questions. However, the incredibly high eigenvalue for the one factor solution prompted the need to examine the data through a one-factor solution for a factor analysis.

While dropping problematic items and rerunning the analysis is often recommended provided that each factor retains at least three items, I needed to consider if this would affect the integrity of the data (Costello & Osborne, 2005). Implications for future use of this survey to measure the three separate subsets of stress are presented in Chapter 5. Because the subsets of stress still measured the main concept of stress, I ran another PAF with the number of factors for extraction set to one. It is also notable to mention the factor correlation matrix obtained from the three-factor solution showed a high correlation amongst the three factors, further validating the one-factor choice (see Table 12).

Table 12

Three-Factor Solution: Factor Correlation Matrix

Factor	1	2	3
1	1.00		
2	.707	1.00	
3	.712	.572	1.00

One-factor solution. For further validation of the one-factor option, I ran another factor analysis for fixed number of factors for extraction set to one with no rotation. The initial factor analysis indicated a high eigenvalue for one factor that accounted for more than half of the variance. The three-factor solution presented seven problematic items and a factor correlation matrix with highly correlated factors. For these reasons, the one-factor solution was run. These results are in Table 13.

Table 13.

One-Factor Solution Factor Matrix

Item	Original Category	Factor Loading	Item	Original Category	Factor Loading
1	PS	.797	13	PS	.221
2	C	.199	14	C	.726
3	R	.758	15	R	.790
4	PS	.764	16	PS	.804
5	C	.587	17	C	.774
6	R	.810	18	R	.778
7	PS	.775	19	PS	.669
8	C	.719	20	C	.725
9	R	.718	21	R	.748
10	PS	.757	22	PS	.754
11	C	.725	23	C	.780
12	R	.682	24	R	.748

Items 2 and 13 are the only items that do not load high on the one factor solution. While these items are lower than the recommended .30 score for clean structure, I chose to examine the item correlations and Cronbach's alpha to help determine whether to keep or remove these two items (Costello & Osborne, 2005).

Correlation and reliability. I obtained a score for corrected item total correlation through the reliability analysis (Table 14). While it is notable that Items 2 and 13 did not correlate well with the other items, it was also notable that the deletion of these items would not significantly increase Cronbach's alpha. Cronbach's alpha for all 24 items was .960. Deleting Item 2 increased Cronbach's alpha from .960 to .962 (see Table 15). Deleting Item 13 increased Cronbach's alpha from.960 to .963. Because of the minimal effect on the reliability, all items were included in further data analyses.

Table 14

Corrected Item Total Correlation

Item	Corrected Item Total Correlation	Item	Corrected Item Total Correlation
1	.774	13	.217
2	.195	14	.712
3	.745	15	.775
4	.748	16	.783
5	.581	17	.764
6	.792	18	.762
7	.758	19	.654
8	.711	20	.707
9	.700	21	.727
10	.743	22	.738
11	.716	23	.769
12	.671	24	.734

Table 15

Reliability if Item Deleted

Item	Cronbach's Alpha if Item Deleted	Item	Cronbach's Alpha if Item Deleted
1	.957	13	.963
2	.962	14	.958
3	.957	15	.957
4	.958	16	.957
5	.959	17	.957
6	.957	18	.957
7	.957	19	.958
8	.958	20	.958
9	.958	21	.958
10	.957	22	.958
11	.958	23	.957
12	.958	24	.958

With N of items 24, Cronbach's alpha is .960

Assumptions. There are three assumptions for conducting a one-way ANOVA. These are normality, equal variances, and independence of samples (Agresti & Finlay, 2008). Each group of the respondents had a sample size larger than 30 (Group 1: $n = 58$, Group 2 $n = 56$, Group 3 $n = 37$). According to the central limit theorem, it is assumed that the response variable is normally distributed (Agresti & Finlay, 2008). Even though the test for homogeneity of variance resulted in unequal variance (Levene's test: for sum scores, $F = 4.43$, $p < 0.05$; for factor scores, $F = 5.15$, $p < 0.05$), the largest variance was no more than four times the smallest variance (for sum scores: the largest is 467.7 for Group 3 and the smallest is 246.6 for Group 1; for factor scores: the largest is 0.89 for Group 3 and the smallest is 0.45 for Group 1). It is generally agreed that the ANOVA test is robust to heterogeneity of variance under this condition ("Cross validated," 2015). It is also assumed that respondents did not communicate with/influence each other while filling out the survey, thus the assumption of independence was met. I accepted the data and did not adjust for the homogeneity of variance test.

Skewness and kurtosis statistics for all items as shown in Table 16 indicated no evidence against the assumption of normality for most items, minus Item 2. However, Item 2 (labeled 1C for the first question in in the communication stress subset) has a high kurtosis value and is positively skewed, suggesting that most respondents chose the *Strongly Agree* or *Agree* option. Figure 2 is a histogram showing the skewness of responses. The majority of respondents chose *Strongly Agree* or *Agree* to the item "I can feel proud of the way I have responded to the special needs of my deaf/hard of hearing child." This item was reverse coded so that the *Strongly Agree* option was 1 and the *Strongly Disagree* option was 5 (the higher the number, the higher the stress). The positive skew on this item indicates that most parents, regardless of disability, feel proud of the way they have responded to their child's needs. Even though the skewness and kurtosis values did not exceed the values for assumption violation, this item could be problematic in the following analyses. Other items appeared to perform well, be roughly normal, and did not show any extreme responses.

Table 16

Group Statistics by Item

Item	Mean	Standard Deviation	Standard Error	Skewness	Kurtosis
1	2.1788	1.40516	.11435	.977	-.468
2	1.5563	.78005	.06348	1.817	4.022
3	3.1523	1.43642	.11689	-.011	-1.501
4	2.1854	1.20777	.09829	.810	-.446
5	2.2781	1.20088	.09773	.711	-.672
6	2.5232	1.28496	.10457	.512	-1.008
7	2.4570	1.27925	.10410	.446	-1.137
8	2.9735	1.49643	.12178	.034	-1.516
9	2.4768	1.32582	.10789	.755	-.695
10	2.6821	1.41596	.11523	.309	-1.368
11	3.1325	1.34499	.10945	-.078	-1.389
12	2.8543	1.31857	.10730	.096	-1.386
13	2.7417	1.25679	.10228	.399	-1.135
14	2.6689	1.17031	.09524	.116	-1.369
15	3.0199	1.42113	.11565	.205	-1.477
16	2.1854	1.28273	.10439	.876	-.421
17	2.7550	1.38548	.11275	.266	-1.329
18	2.5828	1.28249	.10437	.553	-.940
19	2.5033	1.27475	.10374	.531	-.995
20	2.4702	1.21000	.09847	.448	-.895
21	2.5033	1.42302	.11580	.746	-.871
22	2.3245	1.13461	.09233	.582	-.825
23	2.6623	1.37058	.11154	.347	-1.278
24	3.1854	1.44409	.11752	-.182	-1.431

Minimum = 1, Maximim = 5, *n* = 151

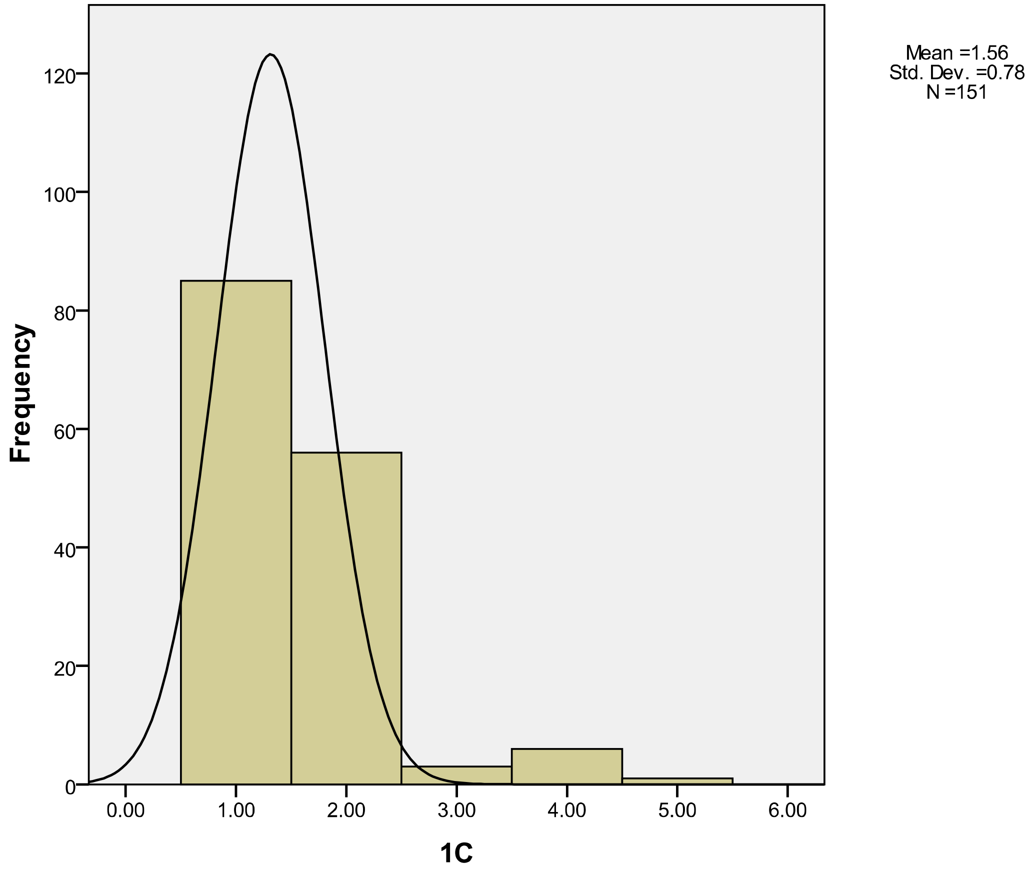

Figure 3. Histogram of item 2

Analysis of variance.

One-way ANOVA. A one-way ANOVA was run using the observed score total for the instrument. This score was obtained using the individual respondents total scores based on their responses to each question using the five-point Likert Scale. The possible range of scores was 24 to 120. Results are presented in Table 17.

Table 17

One-Way ANOVA: Observable Scores

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	20797.65	2	10398.82	27.65	.000
Within Groups	55669.93	148	376.15		
Total	76467.58	150			

p = <.05

In addition, a one-way ANOVA was run using the latent scores obtained from the factor analysis and saved as regression scores. These results are presented in Table 18.

Table 18

One-Way ANOVA: Latent Scores

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	39.71	2	19.85	27.90	.000
Within Groups	105.30	148	.71		
Total	145.01	150			

p = <.05

The results for both observable (total instrument score) and latent (regression score) scores indicated similar results. F scores were close, being 27.65 and 27.90 respectively. Significance was found between groups with *p* = .000.

Post-hoc tests. I ran Post-Hoc tests using Tukey for both observable and latent scores to determine where the significance occurred. Both tests provided similar results. Significance at the p = .000 level was found for both observable and latent scores between the unilateral hearing loss group and the bilateral hearing loss group and between the unilateral hearing loss group and the cochlear implant group. No significance was found between the bilateral hearing loss group and the cochlear implant group.

Table 19

Post-Hoc Tukey Tests for Observable Scores

(I) Group	(J) Group	Mean Difference (I-J)	Standard Error	Sig.
unilateral hearing loss	bilateral hearing loss	-21.07204*	3.63349	.000
	cochlear implant	-27.42870*	4.08062	.000
bilateral hearing loss	unilateral hearing loss	21.07204*	3.63349	.000
	cochlear implant	-6.35666	4.10890	.272
cochlear implant	unilateral hearing loss	27.42870*	4.08062	.000
	bilateral hearing loss	6.35666	4.10890	.272

* The mean difference is significant at the 0.05 level.

Table 20

Post-Hoc Tukey Tests for Latent Scores

(I) Group	(J) Group	Mean Difference (I-J)	Standard Error	Sig.
unilateral hearing loss	bilateral hearing loss	-.90909075*	.15802554	.000
	cochlear implant	-1.20714927*	.17747199	.000
bilateral hearing loss	unilateral hearing loss	.90909075*	.15802554	.000
	cochlear implant	-.29805852	.17870202	.221
cochlear implant	unilateral hearing loss	1.20714927*	.17747199	.000
	bilateral hearing loss	.29805852	.17870202	.221

* The mean difference is significant at the 0.05 level.

Additional tests. ANOVA and post-hoc tests determined the relationship between groups. Means for each group's overall test scores clearly showed that the cochlear implant group had the highest mean while the unilateral hearing loss group had the lowest. While this provided information in relation to overall stress levels of parents as influenced by the type of hearing loss, it did not provide any information about responses to specific questions. I wanted to know if the cochlear implant group had the highest mean on every item of the scale, so further descriptive analyses calculated mean scores by group for each item. These are reported in Table 21. Only questions that loaded correctly into the original subcategories of parental stress (PS), communication stress (C), and relationship stress (R) as determined by the three-factor solution (Table 11) were examined.

Table 21

Items by Mean – True Factor Loadings for Three-Factor Solution

Item	True Category	Unilateral Group Mean	Bilateral Group Mean	Cochlear Group Mean
1	PS	1.66	2.30	**2.81**
4	PS	1.83	2.22	**2.70**
7	PS	1.76	2.66	**3.24**
10	PS	1.90	3.07	**3.32**
16	PS	1.59	2.52	**2.62**
19	PS	1.86	2.61	**3.35**
22	PS	1.86	2.52	**2.76**
5	C	1.69	**2.68**	2.59
8	C	1.97	**3.71**	3.43
11	C	2.31	**3.71**	3.54
14	C	2.10	3.00	**3.05**
17	C	1.90	**3.36**	3.19
23	C	1.78	**3.23**	3.19
3	R	2.43	3.34	**4.00**
12	R	2.45	3.07	**3.16**
15	R	2.24	3.20	**3.97**
24	R	2.47	3.34	**4.08**

The cochlear implant group had the highest mean for all questions except those addressing communication stress. Five of the six items that were determined to clearly address communication stress had higher mean scores for the bilateral hearing loss group than the others. Only Item 14 (I tend to treat my deaf/hard of hearing child like a child who is a good deal younger) obtained a higher score for the cochlear implant group (*m* = 3.05) than the bilateral hearing loss group (*m* = 3.00), though only by 0.05. Three items elicited the highest means for the entire survey. Item 3 (Differing opinions from professional have made it hard for me to make decisions about the education of my deaf/hard of hearing child) had a mean score of 4.00 for the cochlear implant group. Item

15 (Many times I have been angry because of the way professionals treated me as the parent of a deaf/hard of hearing child) had a mean score of 3.97 for the cochlear implant group. Item 24 (It is frustrating for me as a parent to have so many different opinions among professionals who work with deaf/hard of hearing children) had a mean score of 4.08 for the cochlear implant group. Items 3 and 24 were also among the three highest means for the unilateral hearing loss group.

Summary

The results of this study indicate that there is a relationship between the independent variables of a unilateral childhood hearing loss, a bilateral hearing loss, or a child with a cochlear implant(s) and the dependent variable of stress in hearing parents. Because the results of the factor analyses indicated one clear factor, hypotheses one, two, and three were not tested. The result of hypothesis four was accepted, as there was, indeed, a difference in total instrument scores amongst the three groups. However, significance was found between the unilateral hearing loss group and the bilateral hearing loss group and the unilateral hearing loss group and the cochlear implant(s) group. No significance was found between the bilateral hearing loss group and the cochlear implant(s) group.

Chapter 5 will provide an interpretation of the data analyses in this chapter and will utilize the results in making further recommendations for research, the potential changes for future use of the survey instrument, and implications for social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to investigate if a relationship existed between the stress levels of hearing parents and the type of their children's hearing loss. Through quantitative procedures, I investigated the relationship between the independent variables of a childhood unilateral hearing loss, bilateral hearing loss, or presence of a cochlear implant(s) and the dependent variable of stress in hearing parents. One hundred seventy-two responses from parents within the state of South Carolina were collected through an online survey hosting website. Of these, 151 were included in the data analyses.

Data analysis measures included ANOVA, Post Hoc Tukey procedures, descriptive analyses, Cronbach's alpha, and factor analyses. A significant difference existed between the unilateral hearing loss group and the bilateral hearing loss group (p = .000), as well as between the unilateral hearing loss group and the cochlear implant(s) group (p = .000). No significant difference existed between the bilateral hearing loss group and the cochlear implant(s) group (p = .272). Through the factor analysis, I also found that the survey measured one factor, stress, well, as opposed to the three factors, parental stress, communication stress, and relationship stress, the original survey measured. For this reason, the first three hypotheses were not tested. The Influence of Childhood Hearing Loss on Hearing Parents was an adapted instrument rated on a 5-point Likert type ordinal scale rating agreement with 24 items that measure stress. Raters agreed with the statement on a Likert scale as follows: 1 = *Strongly Disagree*, 2 =

Disagree, 3 = *Not Sure*, 4 = *Agree,* and 5 = *Strongly Agree*. Items 2, 5, 6, 9, 13, 18, and 20 were reverse coded in SPSS, as the most stressful response for these items would have been Strongly Disagree. This resulted from adapting the original survey, The Impact of Childhood Hearing Loss on the Family, which did not make the choices identical for each item, but instead listed the most positive response at the far right (Meadow-Orlans, 1990). Scores on these items combined to create the observable total instrument score. Total instrument score using latent variables from the factor analyses were also used to create the latent total instrument score. Assumption requirements for ANOVA testing were met. The one-way ANOVA analyses for both observable and latent scores showed significance of $p = .000$. Post Hoc tests revealed this significance was between the unilateral hearing loss group and the bilateral hearing loss group, as well as the unilateral hearing loss group and the cochlear implant(s) group. An examination of the means for each item revealed that the bilateral hearing loss group scored higher on five out of six items that measured communication stress. The cochlear implant group scored highest for all other items on the instrument. The unilateral hearing loss group scored lowest for all items.

Interpretation of the Findings

Hypotheses Testing

In this study, I sought to determine what relationship, if any, existed between the independent variables of a unilateral childhood hearing loss, a bilateral childhood hearing loss, or a child with a cochlear implant(s) and the dependent variables of parental stress, communicative stress, and relationship stress. Factor analyses revealed that the survey truly measured only one factor, which was stress. Therefore, no analyses were conducted for Hypotheses 1, 2, or 3.

Results of the ANOVA and Post Hoc analyses showed the relationship between unilateral hearing loss groups for overall test score were significantly different from overall test scores for both bilateral hearing loss group (p = .000) and cochlear implant(s) group (p = .000). In Null Hypothesis 4, there was no difference in overall instrument scores of hearing parents among unilateral, bilateral, and cochlear implant groups, was rejected.

Total Instrument Score Interpretations

The cochlear implant group had the highest mean for both observable and latent total instrument scores. Cochlear implants are an elective surgery for parents, meaning that even though children may qualify, parents have the option to choose to implant their child, unilaterally or bilaterally, or not to implant their child at all. Some parents felt the surgeries were necessary and not a choice, even when the potential outcomes were really unknown (Nelson, Caress, Glenny, & Kirk, 2012). Simply making the decision to implant a child is difficult and stressful (Christiansen & Leigh, 2004). Some scholars have found no difference in stress between parents of children with a hearing loss and those without (Pipp-Siegel et al., 2002). The need to make a decision about the implantation of their child while simultaneously dealing with new and often foreign information and navigating the grief process can make cochlear implants a source of stress for parents (Hyde, Punch, & Komesaroff, 2010; Pipp-Siegel et al., 2002). Parents are often experiencing the world of hearing loss for the first time at the diagnosis of their child.

They have a need to obtain and process all possible routes of amplification and education and the potential outcomes of each, while analyzing and making decisions that work within their own personal contexts. Working with service providers who are on either side of the medical vs. cultural model debate, described in more detail in the relationship items part of the results section, parents of children with cochlear implants have a vast array of decisions to make in a fairly short amount of time; this may help explain the highest means on total instrument score analyses.

Cochlear implants can lead to higher levels of stress in parents given the nature of language development in children with hearing loss. Parents of children with cochlear implants may experience higher stress from communication issues (Sarant & Garrard, 2013). Language ability has a direct relationship with parental stress, and decreased language abilities have been found in multiple studies of children with cochlear implants (Hintermair, 2006; Quittner et al., 2010; Sarant & Garrard, 2013). Input received from hearing aids and cochlear implants is “not as detailed as that received by hearing children, and these technologies do not result in [deaf and hard of hearing] children becoming ‘just like’ hearing children” (Lederberg, Schick, & Spencer, 2013, p. 16). In addition, the age of activation of cochlear implants was found to be related to language outcomes in that the higher the age, the poorer the outcomes (Sarant & Garrard, 2013). The difference between expected and actual spoken language outcomes of children may also help explain the higher total instrument scores for the cochlear implant group.

Parents report stress related to the amount of appointments with doctors, therapists, audiologists, and other professionals related to the use of cochlear implants and the development of language as well as managing the implants (Sarant & Garrard, 2013). There is a high level of involvement required during the time immediately following implantation and thereafter to ensure optimal benefit from implants (Geers & Brenner, 2003; Punch & Hyde, 2010). These additional demands on time may certainly affect the response of parents of children with cochlear implants on the total instrument score.

Item Mean Interpretations

An examination of item mean scores showed that while the cochlear implant group did have the highest mean for most items, the bilateral hearing loss group had the highest mean for five out of six items determined by the three-factor solution to truly measure communication stress. Because some items did load into intended categories when the three-factor solution was ran, it warranted a look at each of these items and their means as they relate to research conducted in the areas of childhood hearing loss and children with disabilities.

Parental Stress Items. Items 1, 4, 7, 10, 16, 19, and 22 loaded as expected onto the general parental stress factor. For all items in this category, the cochlear implant(s) group had the highest mean score and the unilateral hearing loss group had the lowest mean score (see Table 22).

Table 22

Parental Stress Items: Means by Group

Item	Prompt	*m* = Unilateral Hearing Loss Group	*m* = Bilateral Hearing Loss Group	*m* = Cochlear Implant(s) Group
1	I often regret the extra time our family must devote to the problems of a hearing loss.	1.66	2.30	**2.81**
4	We have more family arguments about our deaf/hard of hearing child than we have about other things.	1.83	2.22	**2.70**
7	Much of the stress in my family is (was) related to deafness (hearing loss).	1.76	2.66	**3.24**
10	My deaf/hard of hearing child's behavior has often been a source of worry to me.	1.90	3.07	**3.32**
16	Because of the hearing loss, it was (is) necessary for me to forget many hopes and dreams that I had for my child.	1.59	2.52	**2.62**
19	In the early years, my child's hearing loss created so many demands that I never had time for myself.	1.86	2.61	**3.35**
22	Parents of deaf/hard of hearing children are expected to do too many things for them. This has been a burden for me.	1.86	2.52	**2.76**

Benzies, Trute, & Worthington (2013) found that mothers of children with disabilities often felt their roles were to cover the usual family responsibilities as well as extend into the areas of service, education, and advocacy for their children. Because cochlear implants require a surgery, healing time, and multiple visits to hearing professionals to set them up, it is possible the cochlear implant group scored higher on items addressing time because of these additional responsibilities, including Items 1 and 22. Parental stress may increase in all groups, but be especially higher in the bilateral and cochlear implant(s) groups because parents have to confront differences between themselves and their child while handling parenting demands that are more challenging because of these differences, as addressed in Items 4, 7, and 22 (Koester et al., 2008; Sardar & Kadir, 2012; Zaidman-Zait, 2008). Because communication development can impact social development, it is possible that the significantly higher scores on Item 10 from the bilateral hearing loss group and the cochlear implant(s) group are a result of delayed communication or communication differences between children and their parents (Calderon & Greenberg, 2008; Marschark, 1993). Studies of children with other disabilities revealed that parents have initial feelings of helplessness, which may be directly related to responses on item 16 (Nybo et al., 1998). The direct relationship between the level of needs of the child and the stress levels of parents, as found by Tadema and Vlaskamp (2009), may help explain the higher responses for cochlear implant(s) group and bilateral hearing loss group than the unilateral hearing loss group for Items 19 and 22.

Communication Stress Items. Items 5, 8, 11, 14, 17, and 23 loaded onto the communication stress factor. For five out of six items in this category, the bilateral hearing loss group had the highest mean score (see Table 23). The cochlear implant(s) group had the highest mean score on only Item 14, with a 0.05 difference in mean score from the bilateral hearing loss group. The unilateral hearing loss group had the lowest mean score for each item. This is the only category in which the cochlear implant group did not have the highest mean score on all items.

Table 23

Communication Stress Items: Means by Group

Item	Prompt	*m* = Unilateral Hearing Loss Group	*m* = Bilateral Hearing Loss Group	*m* = Cochlear Implant(s) Group
5	My communication skills are quite adequate for my child's needs.	1.69	**2.68**	2.59
8	I wish I could communicate as well with my deaf/hard of hearing child as I do with hearing child(ren).	1.97	**3.71**	3.43
11	I wish some of the other members of my family could communicate more easily with my deaf/hard of hearing child.	2.31	**3.71**	3.54
14	I tend to treat my deaf/hard of hearing child like a child who is a good deal younger.	2.10	3.00	**3.05**
17	My deaf/hard of hearing child is often left out of family conversations because of communication needs.	1.90	**3.36**	3.19
23	There are many things I can't seem to communicate to my deaf/hard of hearing child.	1.78	**3.23**	3.19

Item 5 responses are of interest, in that while the mean score for the bilateral hearing loss group was highest, they were only .09 above the cochlear implant group, compared to .99 above the unilateral hearing loss group. The minimal difference between the bilateral hearing loss group and the cochlear implant group indicates that the parents in both of these groups feel their communication skills are not as sufficient as the parents in the unilateral hearing loss group do. Communication skills required for children with a bilateral hearing loss may include speech, a signed language, or a combination of the two depending on the degree of hearing loss. The cochlear implant group may be assumed to use spoken language, but sometimes use a signed language or sign system depending on the needs of the individual child. Of key importance to note is that when the cochlear implant receivers are not present (removed from the head of the child for any reason) or the batteries are dead, the child is essentially deaf, placing them in the bilateral hearing loss group with no useable hearing. While some research has found that one aspect of lower stress levels of parents of children with cochlear implants could be the ability of the child and the family to communicate effectively, the relatively high scores from the cochlear implant(s) group do not support this. These findings do support prior research that found that parental stress increased due to communication issues between parents and their deaf/hard of hearing children (Loots et al., 2005; Pipp-Siegel et al., 2002; Sardar & Kadir, 2012; Zaidman-Zait, 2008).

Research on language intervention for toddlers with disabilities found that while there was not a significant difference in parental stress pre and post intervention, parental stress was twice as likely to decrease when the child’s expressive language increased (Smith et al., 2011). In addition, parental stress is higher when deaf children do not communicate orally or hearing parents are unable to communicate effectively through a signed language, as hearing parents experience language barriers with their own children (Pipp-Siegel et al., 2002; Sardar & Kadir, 2012; Stobbart & Alant, 2008; Zaidman-Zait, 2008). Responses to items 8 and 23 add to these findings. Parents in the bilateral hearing loss group scored highest for both of these items, with a greater difference between their response and that of the cochlear implant(s) group for Item 8 than Item 23. The difference between the highest mean for Question 8 (the bilateral hearing loss group) and the lowest mean (the unilateral hearing loss group) was 1.74. This indicates that while there are some parents who felt they had difficulty communicating with their child with a unilateral hearing loss, it is significantly less an issue than it is for parents of children who have a bilateral hearing loss or a cochlear implant(s). The same is true of Item 23, with a mean difference between the highest and lowest of 1.45.

Conversation with family members elicited similar responses, as evidenced by Items 11 and 17, with a difference of 1.40 and 1.46, respectively, between the highest and lowest mean scores. The difference between the bilateral hearing loss group and the cochlear implant(s) group was .17 for both items. This supports prior research that asserts that language can create stigmas from outside the group and that family conversational styles can affect the child's level of participation (Bodner-Johnson, 1991; Meadow, 1975). Other research has revealed that interaction between hearing family members and children with hearing loss are less than ideal (Pipp-Siegel, 1998). The findings from the items in this study that truly measured communication stress help to extend this area of knowledge.

Relationship Stress Items. Items 3, 12, 15, and 24 loaded onto the relationship stress factor. The cochlear implant group had the highest mean score for each item in this category (see Table 24). The unilateral hearing loss group had the lowest mean score for all items in this category.

Table 24

Relationship Stress Items: Means by Group

Item	Prompt	*m* = Unilateral Hearing Loss Group	*m* = Bilateral Hearing Loss Group	*m* = Cochlear Implant(s) Group
3	Differing opinions from professionals have made it hard for me to make decisions about the education of my deaf/hard of hearing child.	2.43	3.34	**4.00**
12	Sometimes my friends/neighbors have been thoughtless or cruel about my child's hearing loss.	2.45	3.07	**3.16**
15	Many times I have been angry because of the way professionals treated me as the parent of a deaf/hard of hearing child.	2.24	3.20	**3.97**
24	It is frustrating for me as a parent to have so many different opinions among professionals who work with deaf/hard of hearing children.	2.47	3.34	**4.08**

Some research has found that parents of children who are deaf struggle with the diagnosis, grief, and system hurdles for services (Freeman et al., 2002). Relationships with services providers was found to be the most frequently cited resource for collaborative problem solving with parents of children with cochlear implants (Zaidman-Zait, 2008). Agencies for early detection of hearing loss cite parental acceptance of the diagnosis and difficulty in reaching parents as the greatest issues they face (Bradham et al., 2011). They also cited relationships with parents and parental involvement as the greatest threats to programs designed to help (Bradham et al., 2011).

Research has clearly shown the importance of collaboration for the success of the student and the family (Turnbull & Turnbull, 2001). Parent empowerment classes have resulted in parents feeling more connected to service providers and more informed of their children's disabilities and needs. This has led to higher levels of trust and lower levels of defensiveness (Murray et al., 2013). As a result of these parent empowerment classes, parents were also able to articulate that they felt teachers viewed their children as a job instead of an individual and that teachers did not see parents as a contributor, which led to increased defensiveness on their parts (Murray et al., 2013).

Of significant importance are the responses from the cochlear implant(s) group to all four items that truly loaded into the relationship stress category. Responses from this group to three of the four items carried the highest means for items on the entire survey. Each of these three items dealt with the way parents feel about opinions of professionals or how professionals have made them feel as parents of a child who is deaf/hard of hearing. Responses to Items 3, 15, and 24 support previous research that found that parents felt judged by the choices and decisions they made about amplification for their children (Jackson et al., 2008). These responses also support the findings that better services for families led to better quality of life for individual family members, as higher responses on these items indicated high levels of stress for the individual completing the current study's survey (Moores et al., 2001). In addition, Zaidman-Zait (2008) reported that parents of children with cochlear implants reported that better relationships with service providers led to increased resources for collaborative problem solving. A study of hearing parents of a deaf child indicated that parents felt the professionals they worked with failed to address the feelings and needs of the family, making adapting to and making decisions for their child's hearing loss more difficult (Spencer, 2008).

Medical Model vs. Cultural Model. In the presence of differing opinions between and amongst service providers, it is understandable that parents would be confused about making the best decisions for their children. This relates to the ongoing debate amongst professionals regarding the cultural model of deafness and the medical model of deafness. The medical model of deafness views the condition of being deaf as pathological, a deficit or deficiency that requires a cure (Lane, Hoffmeister, & Bahan, 1996). The cultural model of deafness is considered a wellness model, viewing deafness not as an impairment but as a condition of being (Lane et al., 1996). Doctors, audiologists, and professionals in the field of "fixing" human deficiencies most often promote the medical model. The cultural model is most often promoted by deaf individuals who share the same use of American Sign Language and view themselves as culturally associated (Lane et al., 1996; Padden & Humphries, 2005). These differences are more evident with the growth, development, and advances in cochlear implants.

Limitations of the Study

The ability to generalize results to other regions is a limitation of this study. Some questions relied on a parental response to educational and medical options as well as advice from professionals. These options and opinions are likely to vary by location, and may provide different responses. There is also limited research on this population for comparison to these results.

The self-reporting nature of the survey may have led to responder attrition. The fact that the deaf community is small and I am a part of this small community may have also led to social desirability and acquiescence bias. The anonymous nature of the study may have helped resolve these limitations, as there was no identifying information collected or connected to any responses.

While response rates did not turn out to be a limitation (172 total responses were obtained), incomplete surveys were an issue. One respondent refused informed consent and 20 additional surveys were incomplete. Eight surveys were missing responses for one to five items. Twelve surveys were missing responses for 20 to 24 items. Because response rates were well above the required sample size for this study, I discarded these 21 responses. The removal of these 8.8% of the total responses is a limitation of the study.

The results of the factor analysis that helped determine the survey truly measured only one factor, stress, not the three factors of parental stress, communication stress, and relationship stress, as originally intended. When I ran a three-factor solution, some items cross-loaded or did not load as expected. This could be a potential validity issue if used to measure three separate subdomains of stress. However, since I chose to run results with only one factor, this was not an issue for the current study. Recommendations for future use of this survey are in the Recommendations section of this chapter.

Recommendations

Future Use of the Survey

One of the limitations of the study was the survey itself. While the original survey measured three subsets of stress, when I conducted the three-factor solution for the factor analysis, the results indicated that not all questions fit into their intended category. Some items cross-loaded into other categories while other items loaded into an unintended category. While there were enough items that fit into each category to reduce the items and run analyses, all items fit into the one-factor solution for stress as the only measurement. The benefit of leaving all items and utilizing this one-factor solution was that all items could remain included and provide an overall score for stress in general that would still address the intent of the study. It is recommended that future use of this survey result in the researcher examining items that cross-loaded or did not load as intended to determine if these statements need to be reworded or eliminated. This section of the chapter will include information on addressing problematic items, potential causes for the positively skewed item (item 2), and demographics to consider collecting during future use of this survey.

Address problematic items. Problematic items (as found in Table 11) were 2, 6, 9, 13, 18, 20, and 21. Items 18 and 20 cross-loaded onto more than one factor while also loading higher in a different category. Items 6 and 21 did not meet the required .30 for their intended factor, but loaded highly on another factor. Items 2 and 13 did not meet .30 for any category and did not load at all onto their intended factors. Item 9 loaded fully on one factor, but not the factor it was intended to. These items should be reviewed for wording and content to help determine what may have led to these issues.

Information about the positively skewed item. Item 2 was positively skewed and would need to be looked at carefully before using this survey again (see Figure 2 in Chapter 4). Item 2 stated, “I can feel proud of the way I have responded to the special needs of my deaf/hard of hearing child.” An examination of pride in parents of children with disabilities may help provide some clarification about the parental responses to this question. It would be prudent to alter the wording, but keep a question addressing this as it could lead to information about family functioning over time. There is a need to examine this as part of a study that looks at the age of the parent, the age of the child, the age of onset of the hearing loss, services received, etc.

As it relates to current literature, child development is impacted by reactions of family members to a disability (Tomasello et al., 2010). Some studies have shown that there is no difference in the daily events, family cohesion, and family functioning between families who have children with a disability and those who do not (Cuzzocrea et al., 2014; Dyson, 2010; Seltzer et al., 2009). Because no research on this exists in the area of hearing parents of children with hearing loss, and positive changes in family attitudes and roles are sometimes reported as a direct result of having a family member with a disability, it is practical to examine this within this group (Seligman & Darling, 2007).

Obtain information across demographics. Future research with this survey should examine how these responses differ based on gender of the child, gender of the parent, age of the child, age of onset, age at time of amplification, and location of the respondents. Because the original study was conducted 25 years ago and the field has grown in a variety of ways, it will be important to see how responses vary based on a variety of demographic factors. In addition, it would help to run more analyses, like regression analysis procedures, that could use this demographic information to identify predictors of stress in hearing parents of deaf and hard of hearing children. This would be of importance to service providers for this population, educators of children with hearing loss, and parents themselves, while helping to potentially make the survey a stronger measure of parental stress in this population.

Gender of parent. In the original study, Meadow-Orlans (1990) found that scores were slightly higher for fathers than mothers on stress and relationship item totals, though only 0.2 and 0.3, respectively. Mothers reported higher stress on the communication scale, but only by 0.1 (Meadow-Orlans, 1990). Research in other areas has found that mothers are more often surveyed than fathers and that measures of stress elicit more significant responses from mothers than from fathers (Dabrowska & Pisula, 2010; Gerstein et al., 2009). Because this information was not collected in this study, it is unknown what percentage of respondents represented mothers and fathers.

Gender of child. The original study found that the sex of the child did not affect scores (Meadow-Orlans, 1990). A study of peer relationships in children with cochlear implants revealed that girls, both deaf and hearing, performed better than boys on tasks of peer competence and prosocial behaviors in (Martin, Bat-Chava, Lalwani, & Waltzman, 2010). An evaluation of psychosocial development in children with cochlear implants found boys were more at risk for psychosocial difficulties than girls with a ratio of 2:1

(Dammeyer, 2010). Gender of the child was found to be a predictor of a measure of language development in young children with cochlear implants (Tajudeen, Waltzman, Jethanamest, & Svirsky, 2010). The current study did not address the gender of the child, but future use of the survey should include this demographic to determine if there is a difference.

Age of parent. The age of the mother was found to be a significant predictor in family adjustment in a study of children with serious disabilities, in that the higher the age of the parent, the higher the level of adjustment (Trute et al., 2012). A study of mothers of children with spina bifida found that the higher the age of the parent, the greater the need for support and resources (Macias, 2003). The demands put on a parent regarding learning another sign language or making appointments and therapy sessions for spoken language outcomes could vary based on age. Because this study did not address this, it is of importance to examine this in the future.

Age of child. Some research has found a direct relationship between the age of the child and the level of family support as well as the age of the child and the level of parental stress (Gelodari et al., 2011; Tadema & Vlaskamp, 2009). The original study found that the age of the child had an inverse relationship with positive relationships with professionals, the younger the child, the more positive the relationships (Meadow-Orlans, 1990). Parents have reported decreased level of trust in healthcare providers as their children became older (Chen & Boothroyd, 2006). While there is research supporting the theory that parental stress increases as children age, peaking in the adolescent years, research specifically with the deaf and hard of hearing population, while limited, does not support these findings (Sarant & Garrard, 2013). A direct relationship between age and coping strategies in children may support findings that child age influences parental stress because children become more able to cope with their own disabilities (Zimmer-Gembeck & Skinner, 2011).

Age of onset or diagnosis. Both the age of diagnosis and the age of access to early intervention services have impact on parental stress (Sarant & Garrard, 2013). Sarrant and Garrard (2013). Diagnosis of a hearing loss prior to 18 months of age has been connected to higher parental stress (Konstantareas & Lampropoulou, 1995). Later diagnosis has contributed to weaker language outcomes, which is a significant cause of stress in parents (Nicholas & Geers, 2003; Sarant & Garrard, 2013; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). A study of hearing sensitivity in individuals with bilateral cochlear implants found that age of onset of deafness caused a difference in localizing to high frequency sound signals (Litovsky, Jones, Agrawal, & Hoesel, 2010). The frequency of sound and speech signals can affect language outcomes for children, which may help predict stress in parents. Age of onset may dictate whether the child was prelingually deaf, meaning language was not learned prior to the onset of the hearing loss, or postlingually deaf, meaning language structures were in place prior to the hearing loss. This would be of interest in identifying predictors of parental stress related to communication.

Age of amplification and services. Early intervention and appropriate interventions have improved outcomes for deaf and hard of hearing children, yet the majority are still behind their hearing peers (Lederberg et al., 2013). Attainment of language has been linked to age at time of exposure (Munoz & Singleton, 2011). Overall performance of implantation has a positive association with younger age (Peterson, Pisoni, & Miyamoto, 2010). A study of language development in children with cochlear implants over time found no relationship with age at time of implantation (Szagun & Stumper, 2012). The study did, however, find that the younger the age of implantation, the faster gains were made (Szagun & Stumper, 2012). Another study found that children who were implanted by 12 months had better language outcomes than those implanted from 13-24 months (Houston & Miyamoto, 2010). Yet another found that children implanted by 12 months have a mean advantage of 8.2% advantage over those implanted between 13 and 24 months and a mean advantage of 16.8% over those implanted from 25 to 26 months in a measure of language development (Tajudeen et al., 2010). The same study found that hearing age, or the amount of time the child has been fitted with working cochlear implants, did not produce any significant differences (Tajudeen et al., 2010). While there are limited studies of age of amplification and receipt of services on language development and outcomes for students, investigating whether this has an influence on the stress of hearing parents is warranted.

Location of respondents. Because services vary by city, state, and region, the location of respondents may be a predictor of stress. In a study of families with a child in early intervention and early childhood settings, the sufficiency of services was found to be a significant predictor of quality of life (Hughes & Valle-Riestra, 2012; Summers et al., 2007). Families of deaf individuals who receive appropriate support services have reported a better quality of life (Moores et al., 2001). The cost of services is a source of stress for parents of children with disabilities (Stabile & Allin, 2012). Parents of British children with cochlear implants indicated that access to as much information as possible prior to implantation was of significant importance (Hyde et al., 2010). All of these factors may vary based on location, and should, therefore, be examined.

Implications

The results of this study bring about interesting implications for professionals working with children with hearing loss and their families. Professionals often believe they are helping, when the results of this study indicate quite clearly that they are an underlying influence on parental stress. From the difference of opinions between and amongst professionals to the way that parents have felt during interactions with professionals, it becomes clearer that professionals working with this population should be presenting information based on evidence and not opinion. This is difficult for several reasons. People working with the deaf and hard of hearing population generally have bias toward one side of the cultural vs. medical debate. In addition, there is a limited amount of research in this field with contradictory findings in what does exist.

This study may help effect positive social change by promoting a greater awareness of the factors that influence stress in hearing parents of children with a hearing loss. Results of this and future research for the individual may be better outcomes educationally, socially, and emotionally. A better understanding of stress in parents may result in the provision of improved services for families of children with hearing loss, affecting both the family and organizational levels. Ultimately, it is my hope that this study be a starting point for further research in the area of parental stress and parental processes for dealing with a childhood hearing loss, influencing social change at the societal and policy level.

Conclusion

My goal for this research was to determine if a relationship existed between the independent variables of a unilateral childhood hearing loss, bilateral childhood hearing loss, or the presence of a cochlear implant(s) and the dependent variable of stress in hearing parents. The results clearly indicated that stress was highest overall for hearing parents of children with a cochlear implant or implants, except on those items that truly measured communication stress. For those items, the bilateral hearing loss group had the highest mean scores.

The value of these findings is in the information it provides to professionals working with this population and their families. Family systems theory focuses on the whole family, not only the individual who is deaf/hard of hearing. Children with hearing loss are affected by the daily lives of others in their household just as they influence the others. The more we, as professionals, know about stress in families raising children with a hearing loss, the better equipped we will be to help families navigate these feelings and actively participate in improved outcomes for their children. If we can understand what influences stress in this population, then we will better know how to provide services that target needs more specifically, leading to better outcomes socially, emotionally, and educationally for all members of the family.

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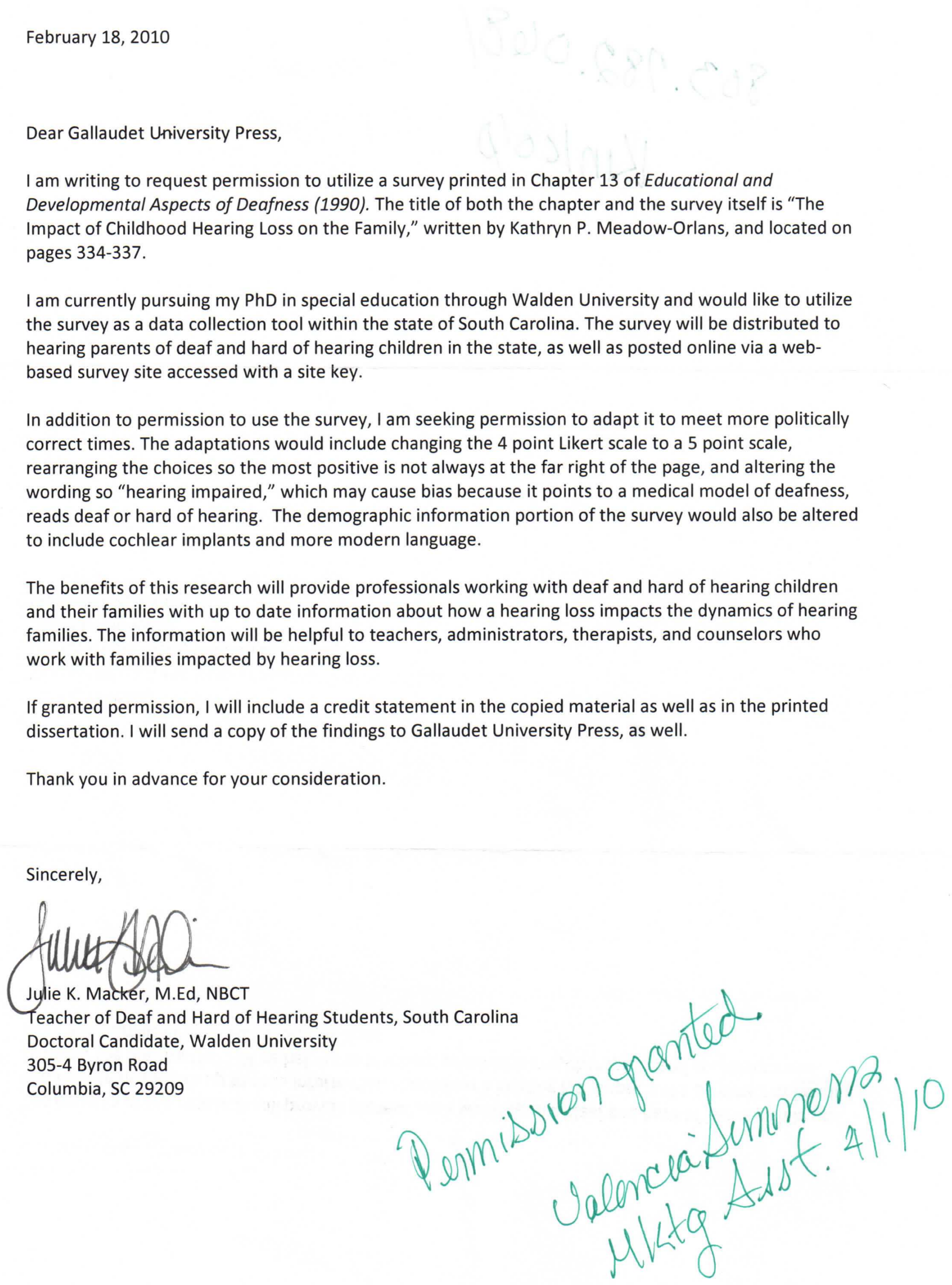
Appendix A: Permission from Gallaudet University Press to Adapt Questionnaire



February 18, 2010

Dear Gallaudet University Press,

I am writing to request permission to utilize a survey printed in Chapter 13 of *Educational and Developmental Aspects of Deafness (1990).* The title of both the chapter and the survey itself is "The Impact of Childhood Hearing Loss on the Family," written by Kathryn P. Meadow-Orlans, and located on pages 334-337.

I am currently pursuing my PhD in special education through Walden University and would like to utilize the survey as a data collection tool within the state of South Carolina. The survey will be distributed to hearing parents of deaf and hard of hearing children in the state, as well as posted online via a web-based survey site accessed with a site key.

In addition to permission to use the survey, I am seeking permission to adapt it to meet more politically correct times. The adaptations would include changing the 4 point Likert scale to a 5 point scale, rearranging the choices so the most positive is not always at the far right of the page, and altering the wording so "hearing impaired," which may cause bias because it points to a medical model of deafness, reads deaf or hard of hearing. The demographic information portion of the survey would also be altered to include cochlear implants and more modern language.

The benefits of this research will provide professionals working with deaf and hard of hearing children and their families with up to date information about how a hearing loss impacts the dynamics of hearing families. The information will be helpful to teachers, administrators, therapists, and counselors who work with families impacted by hearing loss.

If granted permission, I will include a credit statement in the copied material as well as in the printed dissertation. I will send a copy of the findings to Gallaudet University Press, as well.

Thank you in advance for your consideration.

Sincerely,

Julie K. Macker, M.Ed, NBCT
Teacher of Deaf and Hard of Hearing Students, South Carolina
Doctoral Candidate, Walden University
305-4 Byron Road
Columbia, SC 29209

Permission granted.
Valencia Summers
Mktg Asst. 4/1/10

Appendix B: Influence of Childhood Hearing Loss on Stress Questionnaire

INFLUENCE OF CHILDHOOD HEARING LOSS ON HEARING PARENTS
A Questionnaire for Parents

Please answer ALL questions as honestly as you can. Circle "SD" if you STRONGLY DISAGREE. Circle "d" if you "disagree." Circle "not sure" if you are unsure. Circle "a" if you AGREE. Circle "SA" if you STRONGLY AGREE.

I often regret the extra time our family must devote to the problems of a hearing loss.	SD	d	not sure	a	SA
I can feel proud of the way I have responded to the special needs of my deaf/hard of hearing child.	SD	d	not sure	a	SA
Differing opinions from professionals have made it hard for me to make decisions about the education of my deaf/hard of hearing child.	SD	d	not sure	a	SA
We have more family arguments about our deaf/hard of hearing child than we have about other things.	SD	d	not sure	a	SA
My communication skills are quite adequate for my child's needs.	SD	d	not sure	a	SA
I feel satisfied with the educational progress of my deaf/hard of hearing child.	SD	d	not sure	a	SA
Much of the stress in my family is (was) related to deafness (hearing loss).	SD	d	not sure	a	SA
I wish I could communicate as well with my deaf/hard of hearing child as I do with hearing child(ren).	SD	d	not sure	a	SA

I have had a lot of good professional advice about educational options for my deaf/hard of hearing child.	SD	d	not sure	a	SA
My deaf/hard of hearing child's behavior has often been a source of worry to me.	SD	d	not sure	a	SA
I wish some of the other members of my family could communicate more easily with my deaf/hard of hearing child.	SD	d	not sure	a	SA
Sometimes my friends/neighbors have been thoughtless or cruel about my child's hearing loss.	SD	d	not sure	a	SA
Family and friends usually treat my deaf/hard of hearing child the same as they would treat a hearing child of the same age.	SD	d	not sure	a	SA
I tend to treat my deaf/hard of hearing child like a child who is a good deal younger.	SD	d	not sure	a	SA
Many times I have been angry because of the way professionals treated me as the parent of a deaf/hard of hearing child.	SD	d	not sure	a	SA
Because of the hearing loss, it was (is) necessary for me to forget many hopes and dreams that I had for my child.	SD	d	not sure	a	SA
My deaf/hard of hearing child is often left out of family conversations because of communication needs.	SD	d	not sure	a	SA
I have no regrets about the educational decisions that have been made for my deaf/hard of hearing child.	SD	d	not sure	a	SA
In the early years, my child's hearing loss created so many demands that I never had time for myself.	SD	d	not sure	a	SA

I feel confident that my deaf/hard of hearing child can handle most situations as well as a hearing child.	SD	d	not sure	a	SA
It was really hard to find a doctor who could tell us that our child has a hearing loss.	SD	d	not sure	a	SA
Parents of deaf/hard of hearing children are expected to do too many things for them. This has been a burden for me.	SD	d	not sure	a	SA
There are many things I can't seem to communicate to my deaf/hard of hearing child.	SD	d	not sure	a	SA
It is frustrating for me as a parent to have so many different opinions among professionals who work with deaf/hard of hearing children.	SD	d	not sure	a	SA

Please indicate your child's hearing level for each ear:

Left ear	**Right Ear**
☐ No hearing loss (20dB or less)	☐ No hearing loss (20dB or less)
☐ Mild hearing loss (21-40dB)	☐ Mild hearing loss (21-40dB)
☐ Moderate hearing loss (41-55dB)	☐ Moderate hearing loss (41-55dB)
☐ Moderate-severe hearing loss (56-70dB)	☐ Moderate-severe hearing loss (56-70dB)
☐ Severe hearing loss (71-90dB)	☐ Severe hearing loss (71-90dB)
☐ Profound hearing loss (90dB and above)	☐ Profound hearing loss (90dB and above)
☐ Cochlear Implant	☐ Cochlear Implant

Appendix C: Informed Consent for Pilot Study

Informed Consent

You are invited to take part in a pilot study of the influence of a childhood hearing loss on the stress of hearing parents. The researcher is inviting hearing parents of at least one child with a hearing loss who lives and receives educational services within the state of South Carolina to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Julie Macker, who is a doctoral student at Walden University. You may already know the researcher as a teacher, but this study is separate from that role.

Background Information:

The purpose of this pilot study is to ensure the questionnaire items are clear and understandable and to help establish that the questions are collecting the data the researcher intends to. The overall purpose of the final study will be to determine if the degree (mild, moderate, moderate-severe, severe, or profound) and laterality (one or both ears) of a childhood hearing loss influences the stress hearing parents experience. This questionnaire should take approximately 15 minutes to complete.

Criteria for Participants:

By participating in this study, you are indicating that you are a hearing parent of at least one child who is:

- age 21 or under,
- has a hearing loss,
- lives in the state of SC, and
- receives early intervention or educational services within the state of SC.

Procedures: If you agree to be in this study, you will be asked to:

- complete an anonymous questionnaire containing 24 items;
- identify your child's hearing level in each ear;
- provide input about the clarity of questionnaire items; and
- return the anonymous questionnaire in the self-addressed stamped envelope

provided within 10 days.

Here are some sample questions:

Each statement requires a response of one of the following: Strongly Disagree, Disagree, Not Sure, Agree, or Strongly Agree

- My communication skills are quite adequate for my child’s needs.
- I can feel proud of the way I have responded to the special needs of my deaf/hard of hearing child.
- It was really hard to find a doctor who could tell us that our child has a hearing loss.

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind before returning the completed questionnaire. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as becoming stressed or upset by sensitive questionnaire items. Being in this study would not pose risk to your safety or wellbeing. You may experience stress and/or anxiety as you think critically about the impact of hearing loss on your family. If this occurs, please contact The South Carolina Department of Mental Health at (803) 898-8581 for assistance.

The potential benefits of this study include providing an outlet of information that may potentially benefit other families in similar situations, generating information for service providers about how a childhood hearing loss influences family dynamics, and allowing parents and guardians an opportunity to share how familial stress, communication, and relationships are potentially affected by a childhood hearing loss. These may, in turn, provide a positive way for parents to help add to a very small pool of knowledge in hopes of helping other families in similar situations.

There is no compensation for participating in this pilot study.

Privacy:

Any information you provide will be kept anonymous. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. The anonymous data will be kept secure by being locked in a fireproof lock box in the researcher's home in both paper and digital formats. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

If you have any questions at any time, you may contact the researcher via e-mail at Julie.macker@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is (612) 312-1210. Walden University's approval number for this study is **05-14-13-0093516** and it expires on **May 13, 2014.**

Please save this consent form for your records.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By returning a completed survey, I understand that I am agreeing to the terms described above.