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Deaf and Hard of Hearing Children in Saudi Arabia: Status of Early Intervention Services

by

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بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

(سُبْحَانَكَ لَا عِلْمَ لَنَا إِلَّا مَا عَلَّمْتَنَا إِنَّكَ أَنْتَ الْعَلِيمُ الْحَكِيمُ)

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ABSTRACT

TITLE: Deaf and Hard of Hearing Children in Saudi Arabia: Status of Early Intervention Services

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The aim of the research was to describe the status of early intervention services provided to families of children with hearing loss in two main state hospitals in Riyadh, Saudi Arabia, from the parent's perspective. As parental satisfaction is frequently included as a component of evaluating services for children with disabilities and their families, it is important to determine their perceptions of the status of EI services and to identify to what extent they benefit from the services provided.

Early intervention becomes possible with hearing screening. Without systematic hearing screening programmes to identify infants with hearing loss early, losses will only be detected after critical language development periods have passed, resulting in severely restricted prospects for literacy, academic, and vocational outcomes.

A descriptive quantitative research design was implemented in order to gather data. A semi-structured interview based on a questionnaire was conducted with 60 research participants from two main state hospitals that provide early detection and intervention services, according to the purposive sampling technique. Descriptive and inferential statistical analyses were performed on the data collected.

The results of this study indicated that participants' children were identified, fitted with hearing aids and enrolled into EI programmes at a significant later age than recommended by Joint Committee on Infant Hearing. Although the amount and

location of intervention services were problematic for some families, the majority were satisfied with the professionals who worked with them and with the ongoing services that were provided. The statistical analysis also showed that a significant relationship was found between the participants' geographical location and timely access to EI services and fitting with amplification; children who lived out Riyadh were later fitted with amplification than those living in the city. Lastly, the delivery of information emerged as a weakness in the EI system for the majority of participants.

The implications of this study are discussed and recommendations regarding future research endeavours are presented.

Keywords: deaf or hard of hearing, developing country, early intervention, family-centered intervention, hearing loss.

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Abbreviations

AABR: Auditory Brainstem Response

DFHH: Deaf or Hard of Hearing

EI: Early Intervention

EHDI: Early Hearing Detection and Intervention

HL: Hearing Loss

KAMC: King Abdulaziz Medical City

KSCDR: King Salman Centre for Disability Research

OAE: Otoacoustic Emission

UNHS: Universal Newborn Hearing Screening

SAHI: Saudi Association for Hearing Impairment

WHO: World Health Organization

CHAPTER ONE

INTRODUCTION AND ORIENTATION

1.1. Introduction

The early years of a child's life are fundamentally important. They are the foundation that shapes the child's future health, happiness, growth, development, and learning achievement at school, in the family, the community, and in life in general. The importance of this period arises from the fact that the brain achieves 90% of its total growth by age three (Karoly, 1998; Cole & Flexer, 2011). The rapid brain growth that occurs at this time of the child's life is believed to be associated with critical periods during which children are uniquely prepared to benefit from developmental stimulation that is matched to their individualized needs and abilities (Mahoney & Wiggers, 2007; Ryugo, Limb & Redd, 2000).

According to Fish (2003), negative experiences at an early age may be difficult to overcome. Most children grow and develop in predictable ways. For some young children, development proceeds at a slower rate or in an atypical fashion. The reasons for a developmental delay may be physical, mental, environmental, or a combination of factors (Fish, 2003). Hearing loss (HL) is one of the factors that may negatively affect a child's social-emotional development as well as the child's ability to learn and to develop language, especially if it occurs in the early period of life. The most debilitating consequence of childhood HL is that it disrupts language acquisition. Therefore, early childhood permanent HL that originates from birth is of special interest particularly in developing countries (Olusanya & Newton, 2007) because of its adverse consequences for speech, language, cognitive, and psychosocial development and the subsequent impact on educational and vocational attainment when the loss is detected late. A child's listening experience in infancy is critical for the development of both speech and language (Cole & Flexer, 2011)

1.2. Importance of early identification and intervention of HL in children

HL is considered one of the most prevalent disabilities worldwide. According to the WHO, over 5% of the world's population (360 million people) have a disabling HL. Of the 360 million people, 32 million are children. The majority of these cases can be treated through early diagnosis and proven intervention strategies (WHO, 2013).

Hearing is critical for the development of speech and language in young children and children with HL may never develop speech and language or the ability to communicate effectively (Tucci, 2010). It has been shown that children who are deprived of adequate, good quality language input in their earliest years are at risk for poor outcomes in both language and subsequent academic endeavours later in childhood (Nicholas & Geers, 2006). The absence of early identification and early management of children who are deaf or hard of hearing may result in lifelong deficits in speech and language acquisition, poor academic performance, personal-social maladjustments, and emotional difficulties for these children (Attias, Al-Masri & AbuKader, 2006).

In 1995, the World Health Organisation (WHO) passed a resolution on the prevention of HL urging governments to "prepare national plans for the prevention and control of major causes of avoidable HL, and for early detection of HL in babies, toddlers and children within the framework of primary health care" (WHO, 1995). Primary prevention through immunization, genetic counselling, and improved antenatal and perinatal care may help to address some environmental causes, such as birth trauma, infection and neonatal jaundice requiring exchange blood transfusion (Smith, Bale, & White, 2005). Without prevention efforts to identify infants at an early stage through systematic infant hearing screening programs, HL will only be detected after critical language development periods have passed, resulting in severely restricted prospects for literacy, academic, and vocational outcomes (Olusanya & Newton, 2007). For this reason early detection of infants with permanent HL through universal newborn hearing screening (UNHS) has been established in many developed countries to ensure that all deaf infants and toddlers are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.

In contrast, in developing countries the detection of HL remains a passive process and occurs as a result of concerns regarding observed speech and language delays or unusual behaviour (Theunissen & Swanepoel, 2008; Swanepoel, Störbeck & Friedland, 2009; Olusanya, 2004). UNHS allows the identification of HL to occur at much earlier ages. Without hearing screening of newborn babies, most of the children who are DFHH will not be diagnosed until between the ages of two and three. In Saudi Arabia prior to the establishment of a UNHS program in 2010, the average age at which these children were identified was around three years and milder HL commonly remained undetected until a child had entered school (Annual Report, King Abdulaziz Medical City, 2012). Recently, however, the number of screened babies was 7504, and for 75% of the screened babies their audiological evaluation had been completed by four to five weeks of age. Screening is only the first step in access to quality intervention (Yoshinaga-Itano, 2004).

Most professionals in communication disorders believe that it is not screening as such that leads to better developmental outcomes but that the age when children begin to have access to language and communication and the characteristics of the intervention are the primary grounds for better outcomes (Yoshinaga-Itano, 2004). The significance of EI is that it makes use of sensitive periods of development in infancy in order to prevent or minimize language, academic, and social delays that often accompany late-identified HL (Moeller, 2000). Furthermore, children entering an EI program as early as 11 months of age have been shown to have higher levels of language development compared to children enrolled at later ages (Moeller, 2000). Therefore, it is important to ensure that children who were diagnosed with HL are enrolled immediately for appropriate EI services which in turn can alter the entire course of their development (Olusanya et al., 2007).

Although 50% of HL could be prevented in developing countries, the availability and cost of health care in these developing nations often makes treatment difficult (Tucci, Merson & Wilson, 2010). In addition to these factors there are also cultural issues contributing to congenital HL. One such factor in many developing countries, particularly in the Middle East, is consanguineous marriage. Due to this circumstance the incidence of HL is actually higher than in most developing nations (Zakzouk, 2002). Austrolabe (2006) indicates that while Western culture might view

consanguineous marriage or marriage among relatives as ill-advised or somewhat distasteful, these marriages have been a common feature of Arab and some Muslim societies such as Saudi Arabia for thousands of years. Although the risk of HL and other devastating congenital handicaps may be marginally increased with the first generation born from such a relationship, the risk increases significantly down the bloodline with each successive consanguineous marriage (Zakzouk, 2002). In developing nations, therefore, there is not only the challenge of healthcare and the distance between hospitals, but cultural issues that also affect the incidence of HL or the commencement of EI services.

1.3. Statement and rationale

Newborn and infant hearing screening is the only way to ensure that infants who are DFHH are detected early enough to access the critical developmental period within the first year of life through intervention (Korver, Konings, Dekker, Beers, Wever, Frijns & Oudesluys-Murphy, 2010). Although the WHO internationally encourages countries to increase prevention efforts and improve access to early detection and intervention services (WHO, 2010), very few developing countries have any systematic newborn or infant hearing screening programs. A previous study in Saudi Arabia revealed that 15% of children under the age of 18 years with HL could have been identified early by UNHS (Hager, 2009). Although some progress has been made in initiating early detection and intervention hospital-based programs in Saudi Arabia, these are still only reaching very limited numbers of people (Olusanya, Wirz & Luxon, 2008). Limited services in some hospitals resulted in families whose children were identified with HL, but the families did not have access to comprehensive information and resources to support their understanding of HL or the services available. Inadequate information or support, or a delay in obtaining comprehensive services, may deprive children of the potential benefits of EI. Osker and Cohen (2003) describe EI as services responding to child and family concerns in order to minimize potential adverse effects and maximize the healthy development of babies and toddlers. A study in Saudi Arabia indicated that the majority of people with disabilities, including DFHH individuals, did not have access to psychological and educational services at an early age (Hanafi, 2007). As a result, the

development level of a child was below average when entering school, which affected his academic achievement and progress negatively (Hanafi, 2007).

The Saudi Care System for the Disabled (2001) defined rehabilitation as a coordinated process including comprehensive medical educational services provided for individuals with special needs as early as possible to help them to reach their maximum potential. EI is part of the rehabilitation system that must be available for each disabled child in the early years of life to provide services and to meet the child's needs during this critical period. EI services have the potential to deliver improved speech, language, and academic development (Yoshinaga-Itano, 2004).

With regard to the high prevalence of HL among children in Saudi Arabia and limited information available on the status of EHDI, there is a critical need to conduct a study to determine parent's perceptions of the current status of EI in Riyadh, Saudi Arabia. As parents' satisfaction is frequently included as a component of evaluating services for children with disabilities and their families (Bailey, Scarborough, & Hebbeler, 2003), it is important to determine the status of EI services from the parent's perspectives and to identify to what extent they feel they have benefited from the services provided. This in turn will provide insight into the aspects of EI services that need to improve in Saudi Arabia. Starting from these requirements, the aim of this study is to determine the status of intervention services for children who are DFHH in Saudi Arabia.

1.4. Outline of chapters

Chapter 1: This chapter provides the introduction, context, and motivation for the research project. The importance of EHDI for children with HL is also discussed. This is followed by an outline of the chapters, as well as a definition of the most important terminology used in this study.

Chapter 2: This chapter provides a literature review of the prevalence of HL internationally and in Saudi Arabia, the prevalence of HL, the etiology of HL, the consequences of HL, the importance of EHDI services, and the status of EI services provided for children with HL in Saudi Arabia, as well as the challenges relating to EHDI in Saudi Arabia.

Chapter 3: The method used to conduct this study is discussed in Chapter 3. The main aim and sub aims are stated. The research design, ethical procedures, subject selection, data collection, and analysis procedures are discussed in detail.

Chapter 4: In this chapter the results of the study are presented and discussed. This is done according the sub aims as stated in Chapter 3, in order to realize the main aim of the research. A conclusion based on the results obtained is given at the end of the chapter.

Chapter 5: In this chapter the results are discussed and evaluated in depth by drawing on and integrating previous research.

Chapter 6: In this final chapter conclusions are drawn from the results and clinical implications of the study are discussed. Lastly, a critical evaluation of the study is provided, as well as recommendations for future research.

1.5. Definition of terms

Hearing loss (HL): Refers to hearing loss greater than 30 dB in the better hearing ear in children (0 to 14 years) (WHO, 2013).

Universal Newborn Hearing Screening (UNHS): A screening process aims to accurately and efficiently separate the vast majority of newborns with good hearing, from those with hearing loss (Aurélio, 2010).

Early intervention (EI): the process of providing services, education, and support to young children who are DFHH at an early age and no later than six months of age (JCIH, 2007).

Age at diagnosis: the day of the conclusive audiologic assessment that determined individual ear/s affected, frequency specific thresholds, and type of HL (Singer et al., 2009).

Delay of diagnosis: Audiologic evaluation done after three months of age (JCIH, 2007)

Age at fitting of amplification: the age at which personal amplification was first fitted to the subject (Sininger et al., 2009).

Delay of fitting: was calculated as the difference between age of diagnosis and age of fitting in months (Sininger et al., 2009).

Age at intervention: age at which any type of habilitative, rehabilitative, or educational program was provided to children with HL (JCIH, 2007).

Delay of intervention: was calculated as the difference between age of diagnosis and age of intervention in months (Sininger et al., 2009).

Saudi Arabian Society for Hearing Impairment: Organization concerned with the rights of people with HL in Saudi Arabia and which aims to integrate them into the society (SASHI, 2014)

King Salman Center of Disability Research: Center for Disability Research in Saudi Arabia (KSDR, 2014)

Disability code: policies for disabled people in Saudi Arabia, which was issued by the Royal Decree No. (M / 37) at the date 23 / 9/1421 23 – 20\12\2000 (KSDR, 2014)

1.6. Summary

It is well known that HL may influence a child's development negatively if the child does not receive early and adequate intervention. The primary goal of EI is to use sensitive periods of development in infancy in order to prevent or minimize language, academic, and social delays that often accompany late-identified HL (Blair, Peterson & Viehweg, 1985; Moeller, 2000). Therefore, it is important to ensure that children who are diagnosed with HL should be enrolled immediately for appropriate EI services which in turn can alter the entire course of their developmental, academic, and vocational outcomes and ultimately reduce the burden of non-communicable diseases such as childhood HL on health and education (Olusanya et al., 2007).

This study will therefore focus on the reported the status of EI services provided for parents of children with HL in Saudi Arabia at two main state hospitals in Riyadh.

CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

Early detection and management of HL are important elements of appropriate support for DFHH children, helping them to enjoy equal opportunities in society (WHO, 2013). DFHH children often experience delayed development of speech, language, and cognitive skills, which may result in slow learning and other difficulties in school. According to the AAP (1999) and the JCIH (2007) children with HL have to be identified early no later than three months of age; use of amplification should be provided within one month of confirmation of HL with subsequent enrolment in an appropriate EI programme before six months of age. Early enrolment in an appropriate intervention programme for children who are DFHH is an effective strategy for age-appropriate language development in infants and toddlers. Therefore, the most important factors in minimizing the impact of HL on a child's development are early detection and intervention services provided to them in the early period of life.

This chapter provides a literature review of HL in children, the prevalence of HL internationally and in Saudi Arabia, the aetiology of permanent childhood HL, consequences of childhood HL, the importance of early hearing detection and intervention, and EHDI services in Saudi Arabia, as well as the challenges faced by EHDI service providers in Saudi Arabia.

2.2. Hearing loss in children

Infants and children require access to all speech sounds for auditory learning. A primary problem with HL is that it interferes with access of sound to the brain (Musiek, 2009). Neural development and organization of the auditory brain centres require sensory input and extensive auditory experience (Estabrooks, 2006; Kilgard et al., 2007; Sharma et. al., 2004; Sharma, Dorman & Kral, 2005).

All types of HL interfere with acoustic access to the brain. The location of the damage in the auditory system determines the classification of HL as conductive,

sensorineural, or mixed (Bess & Humes, 2003; Northern & Downs, 2002). Normal hearing sensitivity in children is between 0 dB and 15 dB at all frequencies in both ears (Cole & Flexer, 2011). Any HL more than 15 dB place the child at risk for non-acquisition of spoken language, learning problems, and academic failure if there is no intervention to access and develop the auditory brain centres with enriched spoken language (Cole & Flexer, 2011).

HL of any type or degree that occurs in infancy or childhood, no matter how slight, warrants auditory management. A minimal HL can seriously affect the overall development of an infant or child who is in the process of learning language and developing spoken communication skills as the basis for literacy and acquiring knowledge (Cole & Flexer, 2011). In addition, these difficulties worsen as the degree of HL increases. If auditory input is inadequate, auditory processing will be disturbed in relation to the severity of the HL (Tibussek, Meister, Walger & Foerst, 2002).

It is important to understand the prevalence, aetiology, and the consequences of HL to provide appropriate intervention, and in so doing overcome the secondary negative effects of HL.

2.2.1. Prevalence of permanent childhood HL

HL is considered one of the most prevalent disabilities worldwide. According to the WHO (2013), there are 360 million persons in the world with disabling HL (5.3% of the world's population), 328 million (91%) of these are adults (183 million males, 145 million females), and 32 million (9%) of these are children. Higher prevalence of childhood HL is associated with lower levels of parental literacy rate and gross national income per capita. The majority of HL cases can be treated through early diagnosis and proven intervention strategies (WHO, 2013).

In many countries, particularly in the Middle East, the incidence of HL is higher than in most developing nations due to consanguineous marriage (Zakzouk, 2002). As pointed out in Chapter One, the risk for HL and other devastating congenital handicaps increase significantly down the bloodline with the first generation of each successive consanguineous marriage. Zakzouk (2002) has conducted a survey

among first and second cousins and found about 66% of the first cousin's offspring were DFHH while the incidence was 37% from a second cousin relationship.

The prevalence of HL also increases among adults above 65 years. Approximately one-third of persons over 65 years are affected by disabling HL (WHO, 2013). The prevalence of HL among aged people in Saudi Arabia has been found to increase markedly with age (10.2% in subjects aged 46 to 50 years, and 38.3% in subjects aged 71 to 75 years) (Hagr, 2009).

The prevalence of HL was also found to vary according to the geographical location in Saudi Arabia. A national project involved with disability among children in Saudi Arabia was conducting during the period 1997 to 2000. The study showed that the prevalence of HL based on geographical locations indicated that around 36.9% of these individuals live in urban areas, while this percentage increases to 63.1% in rural areas. This study also indicated that the highest percentage of HL occurs in the southern region (31.4%), while the Eastern Province represents a smaller proportion (7.7%). The reason for this phenomenon in Saudi community, in addition to their custom of interrelated marriage, is that they have large families and a rapidly growing population. The siblings of consanguineous marriages have a significantly higher incidence of autosomal recessive diseases, including HL (Zakzouk, 2002).

According to the Saudi Arabian Society for Hearing Impairment (2007), the total incidence of HL has reached 13% of the population; 10.4% of the causes of HL are treatable, 1.1% has sensorineural HL, and 1.5% showed mixed HL. In around 39% of the cases, HL is acquired during pregnancy or after birth, and in 37% of the cases the HL is inherited.

The prevalence of HL in the developing world is largely unknown due to the paucity of up-to-date and representative epidemiological data on HL (Olusanya, Luxon & Wirz, 2004). The lack of relevant data in the developing world has been attributed to several factors such as poor socio-economic conditions in developing countries (Mencher & Devoe, 2001) or limited resources available (Olusanya, 2000). The lack of epidemiological data of HL is a specific problem in Saudi Arabia and unfavourable attitudes towards childhood hearing impairment seems to be the main reason (Stephens & Eisenhart-Rothe, 2000).

The prevalence of HL should be assessed in various age groups in urban and rural communities, and in communities with special needs (WHO, 2010). However, like in other developing countries such as South Africa (Swanepoel, 2006), screening for HL is implemented in only some public hospitals in Saudi Arabia, mostly in urban regions, and only limited numbers of people are reached (Olusanya et al., 2008). Essential data on the prevalence and pattern of HL are difficult to obtain without NHS (Olusanya, 2004). The prevalence of HL in Saudi Arabia might be higher than that estimated in the previous reports, as could be demonstrated if there were a data management system such as UNHS capable of reporting reliable numbers and percentages of children who are DFHH in all regions of Saudi Arabia. For this reason, the approval of establishing UNHS in 2010 with Resolution # 05-02-2010 mandates providing hearing screening for all newborn babies in well-baby nurseries (KAMC, 2010). Despite this mandate for providing hearing screening services for all newborns, only some of the public hospitals established screening programmes because of limited funding for UNHS programmes.

2.2.2. Aetiology of permanent childhood HL

Hearing losses that occur in the early years of a child's life are classified into congenital or acquired HL. A HL is typically *congenital* when it develops before, at, or shortly after birth but prior to the learning of speech and language, usually before age three (Bess & Humes, 2003). In contrast, *acquired* HL develops after speech and language skills have been acquired (Cole & Flexer, 2011). The aetiology of permanent childhood HL includes numerous factors. Permanent HL is an aetiologically heterogeneous condition attributable to genetic and environmental causes (Olusanya et al, 2007). Determining and understanding of these factors may guide the audiologist in establishing the course of intervention, because it is known that certain aetiologies result in certain types of HL (Ohlms, Chen, Stewart & Franklin, 1999; Morzaria, Westerberg & Kozak, 2004).

The causes of HL are divided into hereditary causes (non-syndromic or syndromic) and congenital /early onset causes which can be prenatal, perinatal, and postnatal (Smith et. al., 2005). According to Morzaria et al. (2004), 22.9% of the causes of HL are considered to be hereditary, of which 3.5% is syndromic HL with identifiable associated abnormalities such as Waardenburg syndrome, Velocardiofacial

syndrome, Down's syndrome, Goldenhar syndrome, and Brancio-oto-renal (BOR) syndrome, whilst the remaining 19.4% is assumed to be non-syndromic hereditary HL without associated abnormalities. Congenital / early onset HL on the other hand, comes from environmental events such as lack of oxygen, bacterial or viral infection (meningitis, measles, chickenpox, influenza, encephalitis, and mumps), noise exposure, head injury, and medications that may damage the inner ear (Cole & Flexer, 2011).

It is important to note that the significance of each aetiological factor varies with the population (Smith, Bale & White, 2005). In Saudi Arabia, a survey of infants and children found that 60% of children surveyed reported a history of Otitis Media. Perinatal infections were common causes of HL in this population, and HL was significantly more common for those pregnancies in which the mother had not had the benefit of prenatal care. The incidence of HL in the children of mothers who had never received antenatal care was higher than for those who received care. Likewise, the incidence of HL in the children of mothers who had a fever during pregnancy was higher than for children of mothers who did not have fevers (Tucci, 2010). Interestingly, whereas most developing countries have high incidences of HL due to maternal rubella infection, Saudi Arabia's rate was low. These rates demonstrate that, although other developing countries encounter HL due to infectious diseases, the requirements for prevention of the infections seem to be quite different from country to country (Tucci, 2010). Knowledge of all the risk factors and causes of HL in children not only assists audiologists in identifying children with HL, but also assists them in planning culturally appropriate intervention and habilitation programmes (Muller, 2012).

2.2.3. Consequence of childhood HL

Hearing is not an isolated occurrence, but the first step in the development of language, reading, and academic skills (Cole & Flexer, 2011). Access to sound is essential for developing spoken language. Spoken language, in turn, has to be developed before it can be used for reading and writing (Muller, 2012). Fundamental to all academic programmes are reading and writing, without which optimal academic development is not possible (Stacey, Fortnum, Barton & Summerfield, 2006). Once academic achievement has been attained it typically furthers

employment in the professional world (Muller, 2012). In brief, listening experience in infancy is critical for the development of speech and language in young children and a strong language base is essential for acquiring academic skills (Cole & Flexer, 2011).

The earlier a HL occurs, the more the HL interferes with development of auditory brain function, unless the child receives timely and effective intervention (Cole & Flexer, 2011). Major changes in auditory processing occur during infancy and early childhood (Moore & Linthicum, 2007). It is believed that infant and childhood deafness has a more devastating effect on auditory development and the development of receptive and expressive language abilities than HL acquired in the teenage or adult years, because sound deprivation interferes with early development processes (Moore & Linthicum, 2007). It has been clearly proven that HL during perinatal months negatively impacts the development of acoustic discrimination and attention to sound stimuli. Sound deprivation particularly in the first two years of life, could lead to deficits in cortical perceptual processes and ultimately affect word learning (Moore & Linthicum, 2007). Therefore, acoustic stimulation is necessary during early infancy to ensure normal neural development and speech development.

The first three years of a child's life are critical for acquiring information about the world, communicating within the family, and developing a cognitive and linguistic foundation which forms the basis of all further unfolding development (Nicholas & Geers, 2006). Childhood HL can isolate deaf children from family members, as well as interfere with normal social relationships outside of the family (Nittrouer, 2010). Consequently, it constrains children's abilities to succeed academically and to eventually follow desired career paths (Nittrouer, 2010). It has been shown that children who are deprived of adequate, good quality language input in their earliest years are at risk for poor outcomes in language and subsequent academic skills later in childhood (Nicholas & Geers, 2006). In addition, poor language skills and parent-child communication interaction early in life are associated with concurrent socio-emotional and behavioural difficulties (Nicholas & Geers, 2006).

A common challenge to children with HL is the inability to hear adequately in a typical listening situation like a classroom (Brown, 2009). Depending on the environmental noise level, distance from talker, and the pattern of HL, a child who

experiences a 30 dB HL can miss 25 to 40 % of the speech signal if audiological management (Hearing amplification and FM system) is lacking (Killion & Mueller, 2010; Martin, 2008; Northern & Downs, 2002). In addition, a child with a 35 to 40 dB HL without hearing technology can miss up to 50% of class discussions, especially with far off or soft voices (Cole & Flexer, 2011). The child also misses passive learning opportunities through being unable to overhear conversation.

Children with a more severe HL (55-77 dB) can miss 100% of classroom content (Killion & Mueller, 2010), and spoken communication must be very close and loud to be minimally understood if amplification technologies are not used (Cole & Flexer, 2011). Without appropriate early and continued assistance, most children with this degree of HL have significant difficulty at school. They experience problems with speech intelligibility, may have an atonal voice quality, and have problematic social interactions (Cole & Flexer, 2011). Children with severe and profound HL cannot hear conversational speech at all (Ling, 2002) and in these cases spoken language will not develop without appropriate early use of technology (auditory brain access) followed by auditory language intervention (Cole & Flexer, 2011). The degree of HL does not determine functional outcomes, however, when there is early use of technology such as hearing amplification, FM systems, and in some cases a cochlear implant along with auditory habilitation services to overcome the secondary negative effects of HL (Cole & Flexer, 2011).

A further consequence of HL is that people who suffer HL have a much higher unemployment rate. Among those who are employed, a higher percentage of people with HL work in the lower grades of employment, than in the general workforce (WHO, 2013). Lack of services and access may be a reason for proportionally higher unemployment among people with HL (WHO, 2013). In addition to its individual effects, HL affects social and economic development in communities and countries. These negative impacts arise from the interaction of HL with the wider social environment, and can be significantly mitigated through early identification and appropriate management of hearing problems (WHO, 2013).

2.2.4. Early hearing detection of and intervention for HL

Early detection and intervention (EHDI) are motivated by the fact that HL in infants interferes with the child's development (White, 2006). The ultimate goal of EHDI is to provide children with HL with optimal and timely opportunities to maximize linguistic development, communicative competence, and literacy development (JCIH, 2007). Children with HL who were enrolled in EI within the first year of life have been shown to have language development within the normal range of development at five years of age (JCIH, 2007). As a result of research already conducted, it is known that children with HL who were identified and received intervention by six months, demonstrate an advantage in overcoming the impact of the HL, and develop better language abilities compared to those who are identified at a later age (Yoshinaga-Itano et al., 2004; White, 2006). This kind of knowledge is the driving force behind the increasing efforts towards EHDI in young children.

Early hearing detection through NHS has assumed as a measure of best practice in health care within the last decade in the developed world (Olusanya, 2005). This reality has not only had far-reaching implications for the involved family of a child with HL, but also for the pediatric audiologist (English et al., 2004; Young, 2002). For this reason early detection of HL through NHS has been established in the developed world to ensure that all DFHH infants and toddlers are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention (Olusanya, 2005).

In developing countries, however, reports have shown that public awareness of and attitude towards childhood disabilities are poor (Olusanya et al., 2004), and this situation may hinder the promotion of EHDI programmes if not properly addressed (Louw & Avenant, 2002). Although there has been a growing demand for EHDI programmes in developing countries, there are still very few of these programmes across the public healthcare sectors (Olusanya, Luxon & Wirz, 2004). Therefore, detection of HL remains a passive process and occurs as a result of concerns regarding observed speech and language delays or unusual behaviour (Theunissen & Swanepoel, 2008; Swanepoel et al., 2009; Olusanya, 2004).

Screening for HL actually lowers the age at which important benchmarks are achieved for children with HL. No other screening tool has demonstrated the same efficacy as a UNHS programme in reducing the age of HL identification (HPCSA, 2007). In addition, parents strongly support infant hearing screening and are in agreement with its benefits (Fitzpatrick, Graham, Durieux-Smith, Angus & Coyle, 2007). Sininger et al. (2009) found that the age of achievement of benchmarks by children who were screened for HL (diagnosis, fitting of amplification, and enrolment in EI) is on target with stated goals provided by the Academy of Pediatrics and the Joint Committee on Infant Hearing. In contrast, children who are not screened for HL continue to show dramatic delays in achievement of benchmarks by as much as 24 months., EI only becomes possible, however, with NHS and has been shown to be efficient and cost effective (Lasisi, Ayodele & Ijaduola, 2006).

The Joint Committee on Infant Hearing clearly states that no NHS programme should be implemented, unless a comprehensive intervention programme is decisively in place (JCIH, 2007). In addition, the JCIH has outlined a number of principles and benchmarks for EHDI systems to maximize the outcome for infants who are DFHH (JCIH, 2007). These benchmarks ensure that follow-up of the early suspicion of HL is accomplished in a timely manner. Without achieving these benchmarks, the more long-term benefits of early identification cannot be realized (Sininger et al., 2009).

An effective and complete EHDI system should have three basic components: newborn hearing screening, audiologic diagnosis, and early intervention. These three components also should contain within each item culturally competent family support, a medical home, data management, legislative mandates, and programme evaluation tools. These services are provided according to an individualized family services plan and in a timely coordinated manner as recommended by JCIH (2007). Children with HL who do not pass screening should have a comprehensive audiological evaluation no later than three months of age, receive amplification within one month of confirmation of HL, and enrolment in early intervention programmes before six months of age. A breakdown in any one of the areas of identification and intervention can reduce the efficacy of addressing and providing the necessary services for a child with HL (Kruger, 2007).

The child's hearing technology is the most important intervention tool, allowing stimulation and growth of auditory centres of the brain during times of critical neuroplasticity (Cole & Flexer, 2011). The purpose of hearing amplification (cochlear implant or hearing aid) is to access, stimulate, and grow auditory neural connections throughout the brain as the foundation for spoken language, reading, and academics (Gordon, Papsin & Harrision, 2004; Sharma & Nash, 2009). Therefore, in order for auditory pathways to mature, acoustic stimulation must occur early and often, because normal maturation of central auditory pathways is a precondition for the normal development of speech and language skills in children (Cole & Flexer, 2011).

Research also suggests that children who receive a cochlear implant very early (in the first year of life) may benefit more from the relatively greater plasticity of the auditory pathways than will children who are implanted later after the developmentally sensitive period (Sharma, Dorman & Kral, 2005). Emerging data from Colorado Project are showing that about 90% of children born with a profound HL who obtain a cochlear implant before they are 18 months old attain intelligible speech. Further, if the cochlear implant is obtained between two and four years of age, about 80% of the children born with a profound HL will attain intelligible speech (Yoshinaga-Itano, 2004; Yoshinaga-Itano, Sedey, Coulter & Mehl, 1998). Therefore, due to the limited time period of optimal neural plasticity, age of implantation and use of hearing amplification is critical - younger is better (Sharma et al., 2004; Sharma et al., 2005; Sharma & Nash, 2009).

Profound HL also results in a considerable cost for both the child and society, with costs expected to be higher in a developing country (Mohr, Feldman, Dunbar, McConkey-Robbins, Niparko & Rittenhouse, 2000; Saunders & Barrs, 2011). However, EHDI has been shown to be efficient and cost effective (Lasisi et al., 2006; White, 2006) and the long-term economic benefits of EHDI for HL indicate reduced costs for specialized education, social welfare, and improved lifetime productivity for an individual with a HL (HPCSA, 2007). In Saudi Arabia children with HL and who are not identified early will generate significantly higher cost than those who are diagnosed early and provided with appropriate intervention (Hager, 2009).

2.3. Early detection and intervention status (EDHI) of HL in Saudi Arabia

Limited information is available on the status of early identification services for infants with HL in Saudi Arabia. Most of the previous studies suggested that the UNHS should be part of the primary healthcare system (Zakzouk, 2002; Habib, 2005; Al-Jifery, 2007; Hager, 2009). According to the WHO (2010) UNHS has been implemented in a hospital based model, in several countries including the U.S.A, U.K, Canada, Germany, Oman and Indonesia. In order to improve coverage, a few countries such as Russia, China, India, and Nigeria have attempted community based models of UNHS. No information was reported regarding UNHS in Saudi Arabia (WHO, 2009). In 2010, UNHS was initiated in King Abdulaziz Medical City (KAMC), Riyadh, following the approval of establishing this UNHS programme as the first hearing screening programme in the Kingdom of Saudi Arabia under the umbrella of the Cochlear Implant Programme in KAMC – Riyadh. The first report of UNHS was published in 2012(KAMC, 2012) revealing that the number of screened babies was 7504, and that 75% of the screened babies had completed their audiological evaluation by four to five weeks of age. Another study conducted at Jeddah in the western region of Saudi Arabia found that the average age of diagnosis of HL was 5.5 months (Habib, 2005).

The recent developments and reports on infant HL in Saudi Arabia have mainly focused on the screening and diagnosis with little information about intervention in terms of amplification or cochlear implantation and the intervention services available. In 2008 The Cochlear and Middle Ear Implant Programme was established to be the most comprehensive programme in Saudi Arabia (KAMC, 2010). Over 8000 newborns have been screened so far and more than 80 implants have been done. In addition, the programme is providing ongoing rehabilitation services such as referral to ENT, counselling for the families of children with HL, and recommendations for the most suitable intervention strategy as well as amplification with an appropriate hearing device (KAMC, 2010). Generally, hospitals that provide EI services in Saudi Arabia are limited to certain regions: King Faisal Medical City, King Fahd Medical City, National Guard Health Affairs, and KAMC in Riyadh (Central region); AL-Dammam Hospital and Al-Kober Hospitals in the Eastern region; and King Fahd Medical City in Jeddah (Western regions).

EI programmes for children with HL are developed with particular attention to the nature and objectives of the programme (Alsabe, 2008). Therefore, at the beginning, the focus was on providing infants with HL with sensory stimulation therapeutic services (hearing amplification). Then the intervention services expanded to include the role of parents and family who have a significant impact on the child's development, because children with HL typically can learn language within their family in an optimally rich environment. That is, verbal interaction occurs frequently and consistently in normal everyday routines which can form the basis for the provision of an auditory based communicative experience. Particularly in the period from birth to two years old, the everyday requirements of family functioning work to support the establishment of regular routines (Cole & Flexer, 2011). Therefore, it is important for families or parents of children who are DFHH to maintain everyday interactions in order to provide an enriched auditory linguistic environment for their children.

Disability in any form is a development issue because it limits access to education and employment, which in turn creates economic and social exclusion. In deaf education in Saudi Arabia, children with HL have the right to be integrated into all levels of education (pre-school, general, vocational, and higher education) that are suitable to their abilities and that are commensurate with their needs (Disability Code, 2014). However, reports indicate that basic early intervention and education up to five years old are not being provided for children who are DFHH in Saudi Arabia (Hualand & Colin, 2008). A combination of delayed detection and inappropriate intervention may result in these children falling behind their normal hearing peers in language, cognition, and social and emotional development. As a result most children with HL, as elsewhere in the developing world, are unable to maximize their linguistic and literacy competence (Olusanya, 2004) and usually end up being enrolled in schools for the deaf after many years of frustrating search for a solution by parents.

In Saudi Arabia, children who are DFHH still receive their education in special education schools (schools specifically for deaf children) or in the regular public schools but not within the regular classroom (Hualand & Colin, 2008). This kind of education system can negatively influence their communication, education, and

social skills, because it interferes with the normal social interaction environment. By the time they leave schools for the deaf at the age of 18 years and over, their reading and comprehension abilities are about 50—60% of that expected at their chronological age (Olusanya, 2004). Therefore, when DFHH individuals in Saudi Arabia enrol in the universities or colleges they struggle with the use of language (Haualand & Colin, 2008). Consequently, vocational achievements are restricted throughout life.

2.4. Challenges of early hearing detection and intervention in Saudi Arabia

It recommended that a policy of UNHS be adopted in all countries and communities with available rehabilitation services (WHO, 2010). One of the main consequences of the lack of legislation in favour of UNHS is the late diagnosis of HL in children and the low rate of children screened. Due to this, many countries are making efforts to adopt and implement laws to implement UNHS and intervention to ensure that all children have their hearing test at the most appropriate time (Aurélio & Tochetto, 2010). In Saudi Arabia, however, there is no specific policy for the early detection of and intervention for HL provided for children and their families starting from diagnosis until entering school.

The disability code policy (2014) defines habilitation as a coordinated process to utilize medical, social, educational, and professional services to enable children with disabilities to achieve their maximum potential. It also aims to help them to adapt to the needs and requirements of their natural and social environment, as well as to develop their capabilities to attain independence and be productive members of society. The code policy also recommends that habilitation services for disabilities should include genetic counselling, and laboratory testing as well as analyses for the early detection of disease and the necessary intervention (King Salman Centre of Disability Research, 2014). However, the secondary prevention strategy of screening infants for the early detection of conditions that cannot be addressed by primary prevention is rare in Saudi Arabia – as it is in many developing countries (WHO, 2009).

A tough challenge faced by some developing countries, especially those classified as low and middle income, is that funding for prevention, early detection, and rehabilitative programmes is severely limited, and therefore, agencies must compete against priorities to treat life-threatening diseases (Tucci, 2010). Although - unlike other developing countries - Saudi Arabia is a high income country, it has been reported that funding for infant hearing screening programmes are also limited (Habib, 2005; Tucci, 2010). The reasons for this are not always financial. Some wealthy countries have fragmented and ineffective programmes while a number of less wealthy countries have very successful programmes (WHO, 2010). In Saudi Arabia it seems that unfavourable attitudes towards childhood hearing impairment are the main reason for the lack of support (Stephens & Eisenhart-Rothe, 2000).

Recently, some hospitals have started providing comprehensive services for DFHH children including EHDI services: King Faisal Medical City, King Fahd Medical City, National Guard Health Affairs, and KAMC in Riyadh, AL Dammam Central Hospital and Al Kober Hospitals in the Eastern region, King Fahd Medical City in Jeddah in the Western regions, and other university hospitals. Extending services of EHDI throughout the country is a critical problem in developing countries such as Saudi Arabia. UNHS has been reported not to be effective in all parts of Saudi Arabia and this inequity could also affect the effectiveness of EI services (Al-Jifery, 2007). Therefore, hospital based screening programmes are essential but it is also necessary to have complementary community based programmes (Olusanya & Somefun, 2009), especially in countries such as Saudi Arabia where EI services are out of reach for some regions such as the Southern and Northern parts of Saudi Arabia where the prevalence of HL is the highest due to consanguineous marriage (Hager, 2013).

Public awareness of and attitudes towards childhood disabilities in developing countries have been reported to be poor in general and often aggravated by customs and beliefs (Olusanya, 2000; Stephens et al., 2000; de Andrade & Ross, 2005; Swanepoel, Hugo & Louw, 2005). Consanguineous marriage is a custom that needs to be discouraged among Saudi culture in order to prevent congenital handicaps such as HL that increase significantly down the bloodline with the first generation of each successive consanguineous marriage (Zakzouk, 2002). There is a need to

increase awareness regarding the consequences of consanguineous marriages as well as the importance of early detection of and intervention for HL among families particularly in the Southern and Northern parts of Saudi Arabia (Hager, 2013).

The implementation of EHDI programmes in developing world often faces obstacles such as lack of a suitable environment for the testing, shortage of ear-care professionals, lack of services for monitoring and control, the geographical location and socio-economic circumstances of the parents, as well as little information about the benefits of EI provided to families of children who are DFHH (Castaño, 2002; Olusanya, 2004). This complicates the process of universalization of NHS and leads to a large number of dropouts before completion of all the necessary steps (Kennedy & McCann, 2004). In Saudi Arabia there are also some challenges that impede the attainment of JCHI benchmarks for intervention including: absence or limited services of detection and EI services, inaccurate diagnosis often due to lack of updated screening tools, inadequate resources in terms of equipment and trained staff, limited qualifications for home visits and lack of knowledge about how to deal with families and children in professional way, lack of training courses for teachers and specialists who deal with disabled children, and finally, lack of coordination among the various agencies involved in EI (4th International Conference on Disability and Rehabilitation, 2014). Little or no attention is often paid to persons with disabilities in the developing world compared to the practice in developed countries (Olusanya, 2004). Children who are DFHH need the community's support, individually and institutionally, and this support should be provided individually and at an early age (SAHI, 2007).

Lastly, a recent study conducted to determine the difficulties faced by families of disabled children demonstrated that economic factors constitute one of the obstacles faced by families of children with disabilities. When families are not able to meet their child's needs this leads to social, psychological, and economic problems, especially for those families with limited income (Tamami, 2014).

In summary, it is clear that early hearing detection and intervention services in Saudi Arabia faces many challenges. It is positive to know that there is a promise to extend the detection and intervention services throughout the country (AL Sheikh, 2013). Another positive factor is that Saudi Arabia is fortunate to have the biggest centre for

cochlear implant in the Middle East achieving more than 400 cochlear implants annually (Shami, 2013).

2.5. Summary

This chapter orientates the reader with regard to the importance of providing children with HL with detection and intervention services as early as possible, and provides a critical evaluation and interpretation of recent and relevant literature. In order to advance understanding of the effect early detection and intervention has on children with HL, the prevalence, aetiology, and consequences of childhood HL and the importance of early detection and intervention services are discussed. In addition, the status and challenges of early detection and intervention services in Saudi Arabia context are examined. This knowledge provides better insight into the detrimental effects that HL has on children's auditory, speech, and language development, as well as on other aspects of their life.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1. Introduction

This chapter presents the research methodology, including the aims of the study, the research design, ethical procedures, participant selection, procedures of data collection and analysis, as well as the reliability and validity of the research.

3.2. Research aims

The aims of the research study were as follows:

3.2.1. Main aim

The main aim of this study was to determine the status of EI services provided to children who are DFHH from birth to five years of age at two main state hospitals in Riyadh, Saudi Arabia, based on their parents' perceptions.

The following sub aims were formulated in order to realize the main aim of the research.

- To determine the nature of EI services provided for the parents of children who are DFHH.
- To investigate the parents' perceptions regarding EI services and the information provided to them and their children who are DFHH.
- To investigate the parents' needs regarding EI services provided to them and their children who are DFHH.

3.3. Research design

The research design is a plan or a blueprint of how one intends to conduct a research project (Mouton, 2001).

A descriptive quantitative research design was implemented in order to obtain valid generalizations (Struwig & Stead, 2001) regarding the status of EI services based on parents' perceptions in two main state hospitals in Riyadh, Saudi Arabia.

Quantitative research is most commonly conducted through the use of a survey of subjects who have been sampled to be representative of the target population (Struwig & Stead, 2001). Therefore, a semi-structured interview based on a questionnaire (Appendix C) was used to collect data in this quantitative study, targeting parents of children who are DFHH with access to EI services in order to obtain their perceptions regarding the services provided to them and their children.

One of the distinguishing characteristics of quantitative research is that it is a formal, objective, systemic process in which numerical data are used to obtain information (Struwig & Steady, 2003). The systemic descriptive technique enabled the present study to employ multiple statistical measures. The primary data of the questionnaire were used to describe variables relating to parental perceptions regarding the status of EI services (Burns & Grove, 2005). The logical place for this quantitative approach, in the form of questionnaire surveys, is in conclusive research projects where information obtained from samples is representative of the population (Struwig & Stead, 2001).

3.4. Ethical considerations

Ethics refer to moral principles or values that generally govern the conduct of an individual or group. The ultimate goal of all scientific research is the search for the truth. Research ethics offer a code of moral guidelines which will help the researcher to conduct the study in a morally acceptable way (Struwig & Stead, 2003). Researchers have a responsibility toward their profession, clients, and respondents and must adhere to high ethical standards to ensure that neither the research nor the information is brought into disrepute.

Most ethical issues in research fall into one of four categories: voluntary and informed participation, protection from harm, right to privacy, and honesty with professional colleagues (Strydom, 2005). These issues are discussed in more depth in the following section.

3.4.1 Informed consent and voluntary participation

In general, research with human beings requires informed consent. That is, participants or legal guardians in the case of children should be fully informed about a research project before they decide to take part (Oliver, 2010). Therefore, written informed consent (Appendix B) was obtained from participants before commencing with the study. The hospitals included in the research were selected because they have EI services provided for their clients. In addition, hospitals where the research was conducted were informed about the intent of the research and a signed letter of consent (Appendix D) granting permission to participate was also obtained. Any participation in a study should be strictly voluntary (Strydom, 2005). That is, the participants' consent to participate in the research should be voluntary, free of any enforcement or promises of benefits unlikely to result from participation. Furthermore the participants were informed that they had the right to withdraw from the study at any time should they wish to do so.

3.4.2 Right to privacy /confidentiality

According to Baxter and Babbie (2005), it is the researcher's responsibility to make a clear statement to participants regarding the confidentiality of the results and findings of the study. All participants' information and responses shared during the study were kept confidential and the results were presented in a confidential manner in order to protect the identities of the participants.

3.4.3 Protection from harm

The researcher should ensure that participants are not exposed to any undue physical or psychological harm (Leedy & Ormrod, 2013). The risks involved for participants in this study did not exceed the normal risk of day to day living. During this study the researcher strived to be honest, respectful, and sympathetic towards all participants. Human participants in research, particularly children and adults with communication disorders, need special protection (Schwartz, 2006). Therefore, the researcher looked for the subtlest dangers and guarded against them (Baxter & Babbie, 2005).

3.4.4 Honesty

Researchers must report their findings in a comprehensive and truly representative manner, without the inclusion of any findings that will mislead or misinform others (Leedy & Ormrod, 2013). Honesty was maintained and plagiarism eliminated by ensuring that all the research findings of other researchers were acknowledged and referenced (Babbie & Mouton, 2005), and the results were reported in a reliable manner.

3.4.5 Internal review boards

Competence on the part of the researcher and the development of an appropriate research design is required for an ethically acceptable study (Leedy & Ormrod, 2013). In order to ensure an appropriate research design, approval of the Research and Ethics Committee of the Faculty of Humanities of University of Pretoria was obtained (Appendix A). The findings of this research will be introduced to the public in written form. The information obtained during the research was conveyed as clearly and accurately as possible (Strydom, 2005).

3.5. Participants

3.5.1. Sampling method

Sampling involves selecting units for analysis (e.g., people, groups, settings), in a manner that maximizes the researcher's ability to answer research questions set forth in a study (Tashakkori & Taddlie, 2010). The sampling method used in this study can be described as non-probability sampling because the researcher had no way of guaranteeing that each element of the population was represented in the sample (Leedy & Ormrod, 2013). In this study 60 participants were selected, 30 from each hospital where the study was conducted, according to specific criteria to be met before being eligible for inclusion in the sample (Babbie, 2010).

3.5.2. Criteria for participant selection

Participants were selected according to the following research criteria. Firstly, participants had to be parents of children with HL who had received EI services in

the two main state hospitals where the research was conducted. Secondly, parents and their children had to have been enrolled in the EI programme of the hospitals for at least six months to be able to evaluate the services. Thirdly, parents of children with additional diagnosed disabilities were excluded. The rationale of this exclusion criterion was that children who are DFHH and have no additional disabilities, when identified early and when treated with appropriate intervention, have the ability to develop language skills within the normal range of development (Yoshinaga-Itano, 2004).

3.5.3. Materials and apparatus for subject selection

Table 1 provides an outline of the materials and apparatus that were used for the selection of participants

Table1 Materials and apparatus for participant selection

Materials and apparatus	Rationale
Medical records of participant in hospital, and audiogram and audiometric test results.	Were used to determine age, gender, whether a child has no additional disabilities except for the HL, and the duration children had been involved in intervention programmes

3.5.4. Procedure for participant selection

- A letter requesting informed consent (Appendix D) was provided by the researcher to the management of the hospitals involved in the research, to be signed and returned to the researcher via email or fax. The permission was granted to conduct the research from two main state hospitals in Riyadh (Appendix D).
- A statistician was consulted prior to the selection of participants in order to determine an adequate sample size.
- A letter requesting informed consent to participate in the study was given to the participants (Appendix B). The letter emphasized that participation was voluntary, participants' answers would be kept confidential, and that there was

no way that they, their child, and the professional with whom they interacted could be identified.

- After informed consent was granted, the participants' medical record was obtained and their personal and audiological information was used to verify that they qualified for participation.

3.5.5. Description of participants

The demographic information of participants in this study is summarized in Table 2.

Table 2: The demographic information of participants (n=60)

Characteristics	Frequency	Percent
Mother	50	83.3%
Father	9	15.0%
Other	1	1.7%
Do you live in Riyadh		
Yes	19	31.7%
No	41	68.3%
Mother's education		
Lower than graduate degree	34	56.7%
Graduate & higher degree	26	43.3%
Father's education		
Lower than graduate degree	24	40.0%
Graduate & higher degree	36	60.0%
Parents blood related		
Yes	37	61.7%
No	23	38.3%
Cause of child's HL		
Unknown	32	53.3%
Meningitis	6	10.0%
Maternal rubella	4	6.7%
Hereditary	11	18.3%
Other	7	11.7%
Child's degree of HL		
Moderate (40-70dBHL)	2	3.3%
Severe (70-90dBHL)	9	15.0%
Profound (90+dBHL)	43	71.7%
I do not know	6	10.0%
Type of hearing device used		
Hearing aid	11	18.3%
Cochlear implant	42	70.0%
Both	7	11.7%

The study sample consisted of 60 participants who volunteered to participate in the study, 30 participants from each hospital. All participants and their children were involved in the EI programmes for an average of 17 months (SD=14.1). Demographic information was collected from the participants to gain understanding

of family characteristics and potential factors that might influence the perception of the participants (Table 2).

The majority of participants (83.3%) were the mothers of the children, 13.3% were fathers and only 3.3% were other relatives. The participants' educational level was high in nearly half of the sample: 43.3% of the mothers had obtained a degree, 60% of the fathers had a degree or higher qualification. With regard to habitation, 31.7% of the participants lived in Riyadh and 68.3% came from a variety of areas outside of Riyadh to receive intervention services for their children. Mothers who work away from home accounted for 33.3% of the sample compared to 93.3% of fathers. The majority (61.7%) of the participants were blood related, and 26.7% of participants had other children with HL, 20% had a second child with HL, and 6.7% had two children with HL. The children's degree of HL ranged from mild to profound: 86.7% had severe to profound HL, 3.3% had moderate HL and the remaining 10% of the participants did not know the degree of HL. Concerning the device used, 70% of participant's children used a cochlear implant, 18% used a hearing aid and only 11.7% used both. Causes of HL were unknown (53.3%); hereditary (18.3%); meningitis (10.0%); maternal rubella (6.7%); premature birth (1.7%); and other causes (10%).

3.6. Data collection

The materials and apparatus used, and procedures that were followed for the collection of data are discussed in the following section.

3.6.1. Materials and apparatus for data collection

A semi-structured interview using a questionnaire (Appendix C) served as the data collection method of this investigation. The aim of the questionnaire was to obtain valid and reliable information from the participants in order to determine the status of EI services provided to them and their children. The questionnaire consisted of three sections.

3.6.1.1. Section A: background and demographic information

The first part of the questionnaire aimed to determine the background and demographic information related to the participants. The questions in this part of the questionnaire focused on obtaining information regarding the age and gender, region, and educational background of the participants, as well as information regarding the degree of HL, age of the child when HL was diagnosed, and age of the child when fitted with hearing amplification. The demographic information was collected to provide more detailed contextual information that can assist with data interpretation (Fitzpatrick et al., 2008). Furthermore, the information was used to ensure the inclusion and exclusion criteria for participation in the study were met, so that the findings could be generalized (Babbie, 2010).

3.6.1.2. Section B: parents' perceptions regarding intervention services

The purpose of this section of the questionnaire was to investigate participants' perception regarding EI services and other related services provided to them and their children. This part of the questionnaire consisted of six main sections including sub-questions. The six main sections aimed to determine the participants' perception regarding the type and nature of the services provided, as well as the extent of information provided to them by professionals of the intervention programme. They had to indicate their satisfaction with the services provided. The last three main sections covered the time it took for the participants to find EI services as well as for the services to commence. Finally participants had to rate intervention services (Bailey, 2004). Understanding the experiences of families can help to determine their needs, and provide input into the development of an EDHI system as well as support other families in the early identification process (JCIH, 2000). It is imperative for professionals who are involved in early hearing loss detection and intervention to understand families' experiences in order to improve the process (DesGeorges, 2003).

3.6.1.3. Section C: parental needs regarding intervention services

A system in which families' needs are met, children identified to be DFHH can reach their full potential (DesGeorges, 2003). The purpose of this section of the

questionnaire was to determine participants' needs regarding EI services and other related services for them and their children who are DFHH. This section of the questionnaire included six categories of possible needs (Bailey & Simeonsson, 1988):

- The need for information. This category focused on the information that participants received from the EI programme which helped them to play an active role in developing their children's communication skills.
- The need for support from other parents of children with HL or from a therapist.
- The need to explain the problem to others such as siblings or friends.
- The need for community services such as locating a doctor or a day care centre.
- The need for financial support, for example for obtaining special equipment or paying for therapy, day care, and other services.
- Finally, there was one additional question requesting more details, comments, and suggestions that would, in their opinion, improve services provided to their children.

3.6.2. Pilot study

A pilot study regarding the questionnaire was conducted prior to the commencement of the study, since it is an excellent way to determine if the questionnaire is feasible, practical, and effective in determining the answer to the aims of the study (Leedy & Ormrod, 2005). A form of non-probability sampling was used to select two participants. The participants were selected based on the criteria of participant selection for the main study.

3.6.2.1. Pilot study procedure

- The participants were provided with verbal information regarding the purpose of the study, the procedure, and the benefits of the research.

- The participants were requested, in person, to participate in the pilot study and signed the letter of informed consent (Appendix B) which explained the purpose of the study and invited them to participate.
- Two participants were interviewed and the researcher completed the questionnaire for each participant. They were then asked to provide feedback about the questionnaire.
- The researcher subsequently re-evaluated the questionnaire, taking the participants' comments and suggestions into account, and made the appropriate adjustments.

3.6.2.2. Results of the pilot study

Information received from participants was analysed in terms of question order, structure, appropriateness, general layout, and clarity. All comments were taken into consideration, to ensure that the questionnaire's content and construct is valid and to provide assurance that the results of the survey are reliable (Table 3).

Table 3: Results obtained from the pilot study

Aspects considered	Comments	Change
Question order and structure	Good	No changes
Appropriateness of the questions	The question enquiring about their occupation was considered too personal	Excluded from the questionnaire
Clarity of the questions	Q14: "number of adults who live at home" – what about children and/or young adults? Q7&8: the double reference to age in "age at which therapy plan was developed" and "age of intervention therapy" was confusing.	Wording of Q14 was changed to: the number of children and adults who live at home Q7 & 8 were combined to be: "how old was your child when she/he commenced speech therapy".
General layout	Good	No changes

3.6.3. Procedure for data collection

Data collection was conducted at two main state hospitals in Riyadh over a period of three months. Permission was obtained to conduct the research at these two main state hospitals (Appendix D). Each of the interviews was started by introducing the

research aim, and explaining confidentiality and the voluntary nature of participation in the study. An informed consent letter (Appendix B) was signed by the participants who consented to participate in the study. The researcher conducted individual interviews using a semi-structured interview based on a questionnaire (Appendix C). It took approximately 30 to 35 minutes for each participant to complete the questionnaire. During the interviews, the participants were asked to give detailed information and examples concerning their perceptions of the intervention service they received. When the responses provided were not clear, the researcher asked additional questions for the purpose of clarification.

3.7. Data analysis

The data was captured in Microsoft Excel and statistical analysis was done using the SPSS programme.

3.7.1. Procedures for data analysis

A quantitative data analysis was used for this study. Measurement and analysis of quantitative data is standardized, numerical, and gives greater objectivity to the results (Gay & Airasian, 2000). In this study, numerical data were obtained from the questionnaire (Appendix C) regarding the status of intervention services provided to the participants. A priori list of codes was developed with codes that corresponded to each questions in the questionnaire. The data were imported in Excel Microsoft to organize and facilitate the data analysis process. For greater objectivity the IBM SPSS Statistics Version 22 software programme was used for the statistical analysis of these data to yield percentage and frequency distributions, which were graphically represented by figures. Descriptive statistics such as the means and standard deviation were used to describe characteristics of participants that were measured on a continuous scale, for example age. Quantitative data usually involves inferential statistics, which can be used to make inferences from the findings (Leedy & Ormrod, 2013). Inferential statistical tests were performed to test for associations between two categorical questions (Chi-Square Test & Kruskal Wallis Test) and to compare mean scores across categorical questions.

3.8. Reliability and validity

According to Leedy and Ormrod (2013), the reliability and validity of measurement instruments influence the extent to which one can learn something about the phenomenon under investigation, the probability of obtaining statistical significance in the data analysis, and the extent to which one can draw meaningful conclusions from the data.

Reliability is the consistency with which a measuring instrument yields a certain, consistent result when the entity being measured does not change (Leedy & Ormrod, 2005). To enhance the reliability of the study, the questionnaire was standardized and coded. To the extent that subjective judgments were required, specific criteria were established (Leedy & Ormrod, 2013) to prevent research bias and to ensure that all respondents participated of their own free will, providing truthful and reliable answers.

Validity refers to the extent to which a research design is scientifically sound and appropriately conducted (Struwig & Stead, 2003). The researcher guaranteed face validity of the questionnaire and only included items that truly measured what they claimed to measure. Content validity was ensured and the questionnaire items represented the necessary aspects of this particular research topic. Construct validity refers to the extent to which a test, or as in the case of this study a questionnaire, measures the logical relationships among variables (Baxter & Babbie, 2005). Therefore, the questionnaire was only formulated after the construct had been clearly defined and only finalised after a pilot study had been conducted to verify its validity. Descriptive validity was maintained throughout the presentation and the discussion of the result and no information was omitted or distorted in order to change the outcomes of the study (Struwig & Stead, 2003).

3.9. Summary

In this chapter the methods used to conduct the research project are summarized. The procedures implemented in the research methodology were dictated by the main aim of the research and sub-aims that were formulated in order to address the research question.

A descriptive research design was used to enable the researcher to draw conclusions about the status of EI services that participants received. Ethical considerations were addressed in terms of the researcher's responsibility toward humans and science. Procedures for participant selection, the materials used as well as data capturing and data analysis were explained in detail in this chapter.

CHAPTER FOUR

RESEARCH RESULTS

4.1. Introduction

Intervention, provided in a timely manner, has been shown to mitigate some of the deleterious effects of early HL (Kennedy, 2006; Moeller, 2000). The current study provides quantitative data describing the state of EI services according to the perceptions of the participants.

This chapter presents results in the form of statistical analysis of the data collected from participants regarding their demographic characteristics and their perceptions as reflected in their responses to the questionnaire (Appendix C). The inferential statistical tests that were performed (Chi-Square Test & Kruskal Wallis Test) were applied to test for associations between two categorical questions and to compare mean scores across categorical questions. The results are presented according to the sub-aims of the research.

4.1.1. Sub-aim 1: Nature of early intervention services

The results pertaining to sub-aim one were derived from questions B5 – B12.

In this study participants were asked to provide information regarding the age of their child at specific points: when a hearing loss or some unspecified form of difficulty was suspected, at diagnosis, when a hearing aid was fitted, and when speech and language therapy was initiated; and also the time interval between these events. The results of these questions are presented in detail in Table 4.

Table 4: Delay of diagnosis and fitting of amplification

Event/delay	Mean (months)	Standard Deviation
Age when suspected	9.3	8.3
Age at diagnosis	13.7	9.3
Age at fitting	20.7	11.6
Delay of diagnosis	4.0	5.5
Delay of fitting	6.9	7.7
Age when intervention commenced	32.8	13.7

The data in Table 4 demonstrate that the mean age of participant suspecting their child's HL was nine months (SD= 8.5). The mean age at which children were diagnosed was 13.3 months (SD=9.3). Hearing aids were fitted at the mean age of 20.2 months (SD=11.6), and the mean age at which speech therapy services were initiated is 32 months (SD=13.7). The average time interval between parental suspicion and diagnosis of HL was four months (mean=4.0, SD=5.4). In addition, the average time interval between diagnosis and hearing aid fitting was approximately seven months (mean=6.9, SD=7.6).

Inferential statistics was applied to investigate the relation between age of diagnosis of HL and fitting of amplification, across residence area of participants. The participants were classified into two groups according to their residence area: participants living in Riyadh, and participants living outside of Riyadh. The results are presented in detail in Table 5.

Table 5: Relation between residence area and age of diagnosis and fitting

Residence area		Age of diagnosis(months)			Age of fitting(months)		
		0 – 6	7- 12	≥ 12	0 – 6	7-12	≥ 12
Living in Riyadh Total= 19	Count	5	9	5	1	10	8
	%	26.3%	47.4%	26.3%	5.3%	52.6%	42.1%
Living outside of Riyadh Total= 41	Count	7	19	15	1	7	33
	%	17.1%	46.3%	36.6%	2.4%	17.1%	80.5%
Total		12	28	20	2	17	41
Chi- Square Test		p=0.616			p=0.012 *(p≤0.05statistically significant)		

The majority of children from both groups were diagnosed between the age of 7 and 12 months: nine (47.4%) of the 19 children living in Riyadh were diagnosed at this age, and 19 (46.3%) out of the 41 children living outside of Riyadh. A small number of children from both groups (n=12) were diagnosed with HL before six months of age: only five (26.3%) from Riyadh compared to seven (17.1%) outside of Riyadh. Fifteen (36.6%) of the children living outside of Riyadh were diagnosed when they were older than 12 months compared to only five (26.3%) diagnosed at the same age inside Riyadh. Statistically there was not a significant relationship between age of diagnosis and the geographical area of participants (Chi- Square Test, p=0.616). In contrast, the relationship between the age of fitting amplification and the geographical area of participants was found to be statistically significant (Chi-Square Test, p=0.012). The majority of children from both groups were fitted with

hearing aids when they were older than six months and only two were younger than six months. Ten out of 19 children (52.6%) living in Riyadh were fitted with hearing aids at age 7 to 12 months, compared to only seven out of 41 children (17.1%) living outside of Riyadh. Only two children, one from each group, had hearing aids when they were younger than six months and most of the remaining children (n=8 or 42.1% living in Riyadh and n=33 or 80.5% living outside of Riyadh) were only fitted with hearing aids when they were older than 6 months of age.

Inferential statistics were used to describe time differences (delay) between age that participants suspected a HL and diagnosis of HL as well as age of diagnosis and fitting of amplification across residence area. The results imply that there was no significant difference in the mean delay between age when HL was suspected and diagnosis of HL ($p= 0.182$) and between the age of diagnosis and fitting of amplification ($p= 0.147$) across the geographical area of participants.

The reasons for a delay of three months or more between the diagnosis of HL and fitting of hearing aid were indicated by 52 of the participants (86.7%) to be the result of too long procedures and waiting for an appointment. The minority of participants reported that the delay was due to financial constraints (n=3; 5%). The remainder of the participants (n=5; 8.3%) had other, different reasons.

In addition, the relationship between degree of HL and age of diagnosis and fitting of hearing aid were also investigated across three age groups (<6 months; 7 to 12 months; older than 12 months) to see whether the severity of HL resulted in earlier diagnosis. The results of the statistical analysis of these variables are displayed in Table 6.

Table 6: Relationship between age of diagnosis and the fitting of hearing aids & degree of HL

Degree of HL		Age of diagnosis (months)			Age of fitting aids (months)		
		0-6	7-12	≥ 12	0-6	7-12	≥ 12
Mild & Moderate Total=2	Count	0	0	2	0	0	2
	%	0.0%	0.0%	100.0%	0.0%	0.0%	100.0%
Severe to profound Total= 52	Count	11	25	16	2	16	34
	%	21.2%	48.1	30.8%	3.8%	30.8%	65.4%
Chi- Square Test		p= 0.125			p=0.595		

According to Table 6, 11 (21.2%) of the children who were diagnosed before six months of age had a severe to profound HL. Only two of the 52 children with severe

to profound HL were fitted with hearing aids at an age younger than six months. No statistically significant difference was found between the severity of HL and age of diagnosis ($P=0.125$), and between the severity of HL and fitting of amplification ($p=0.595$).

With regards to the modes of communication that were used at home and in the early EI programme, 37 of the participants (61.7%) communicated with their children only through speech at home, and 19 (31, 7%) used some form of sign language in combination with speech to help their children to communicate effectively. The data also showed that the majority of participants indicated that speech/oral communication was the main method used to communicate with their children at EI programmes.

4.1.2. Sub-aim 2: Parents' perceptions regarding EI services

The results for this section were derived from questions C4, C5, E3, G1, G2, F1 and F2 in the questionnaire.

All participants were satisfied or very satisfied regarding the intervention services provided to them and their children. Participants' perceptions regarding the level of quality of EI services are presented in Table 7.

Table 7: Rating the perceived level of the quality EI services

Rate	Frequency	Valid Percent
Excellent	17	28.3%
Very good	20	33.3%
Good	23	38.4%
Poor	0	0

As evidenced in Table 7, more than 75% of the participants agreed that the intervention programme helped them to learn activities to use with their children at home such as language activities and auditory training. In contrast, participants' dissatisfaction was centred on the time taken to find professionals providing intervention services, and for the services to commence. Inferential statistical analysis was also carried out to investigate if residential area significantly affected the time to find professionals providing EI services. The results are presented in detail in Figure 1.

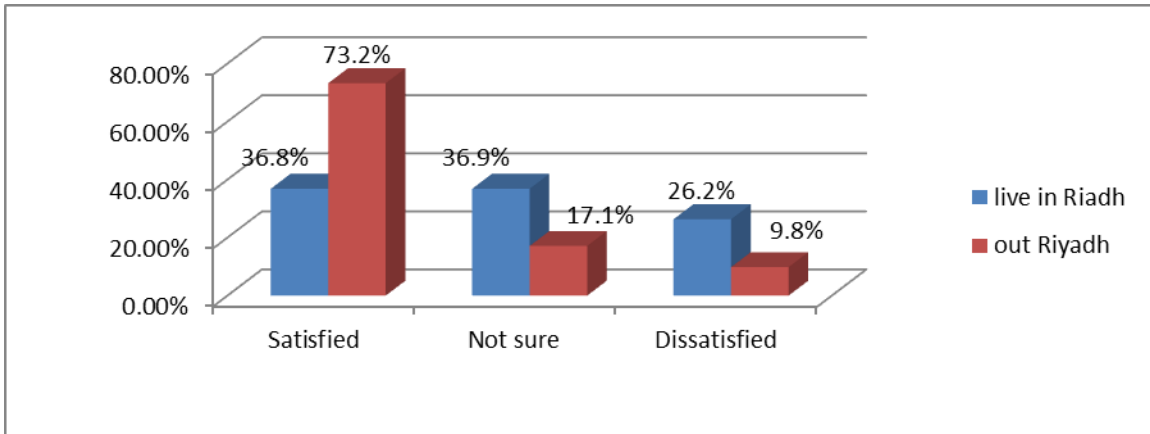


Figure 1: Participants' perception of the time it took to find professionals providing EI services.

The inferential analysis of the results in Figure 1 indicates that there was a significant relationship between whether the participants live in or outside of Riyadh and the time it took to find professionals providing intervention services ($p= 0.026$). Thirty of the participants (73.2%) from outside Riyadh were not satisfied with the time it took to find services in comparison to only seven participants (36.8%) from Riyadh. In addition, the time elapsed before commencement of services was also problematic for most of the participants from outside Riyadh. The results of inferential statistical analysis of participants' perceptions of time lapse for the commencement of services are presented in Figure 2.

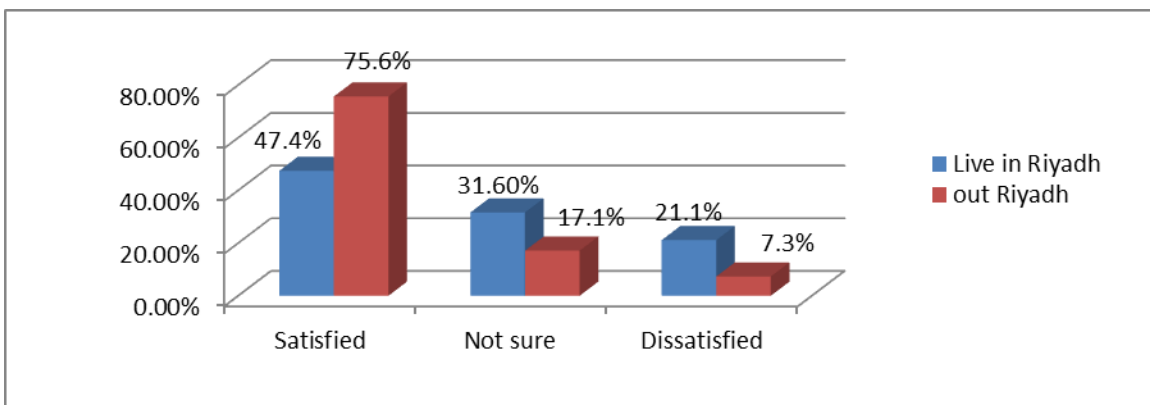


Figure 2: Participants' perceptions of the time lapse for the commencement of services

Figure 2 reveals that one third of participants (75.6%) from outside Riyadh indicated that it took them too long to get the services to commence, in comparison with only nine (47.4%) participants from Riyadh. However, no significant statistically correlation was found between the two groups ($p= 0.086$).

More than half of the participants (66.7%) indicated that the number of therapy sessions was less than needed. The results in this regard are presented in detail in Figure 3.

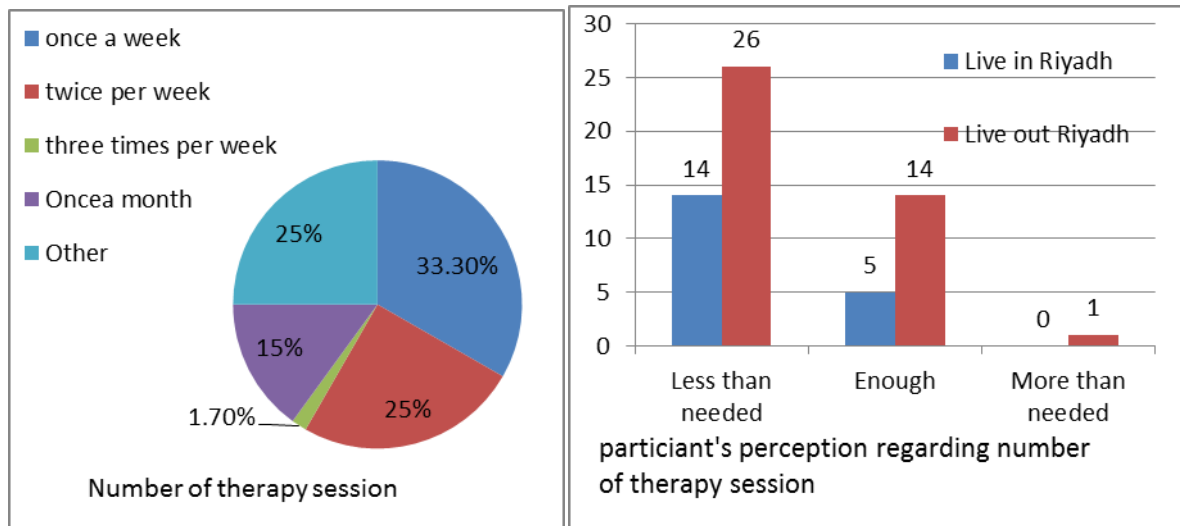


Figure 3: Participants' perception regarding the number of therapy sessions

Figure 3 indicates that 33.3% of participants had weekly sessions, 25% had session twice per week, 1.7% three times per week, 15% had one session every month, and the remainder (25%) of participants selected "other". Inferential statistical analysis was applied to determine the relationship between participants' residence area and the number of therapy sessions. Although the majority of participants, particularly those residing outside of Riyadh, reported low levels of satisfaction with the number of therapy sessions and indicated that it was less than they needed, no significant correlation was found between the number of sessions and the participants' residence area ($p=0.703$).

Participants were also asked if they discussed their concerns with a doctor or other professional when they suspected that their children might have a HL. All participants indicated that they discussed their concern with a primary care doctor; 28.3% of them feel that the first contact was not helpful, while 58.3% feel it was helpful and 13.3 % reported that it was very helpful.

4.1.3. Sub-aim 3: Parents' needs regarding early intervention services

The results for this section were obtained from questions I2-I10, J1-J9, K1-K3, L1-L3, M1-M2 and N1-N2 of the questionnaire. The results regarding participants' needs for support and information from EI services are presented in Table 7.

Table 7: Participants' needs regarding EI services

Classification	Need help	Do not need help
Parents' need for information		
Development of child's speech and language skills	96.7%	3.3%
The services presently available to my child and how to handle my child's behaviour	95%	5%
How to play with my child and talk to him	93.3%	6.7%
Techniques to use at home and selection of communication methods	86.7%	13.3%
Parents' need for support		
Talk to my child's teacher or therapist	75%	25%
Meet more regularly with a counsellor	61.7%	38.3%
Explaining to others		
Explaining my child's condition to her/his siblings or other children	66.7%	33.3%
Responding to others' questions regarding my child's condition	65%	35%
Community services needs		
Locating a doctor or therapist	80%	20%
Locating a day care facility or preschool placement	78.3%	21.7%
Financial needs		
Getting special equipment for my child	58.3%	41.7%
Paying for therapy, day care, and other services	48.3%	51.7%

According to the data in Table 7, the majority of participants showed a need for information related to their children's development, such as: the development of my child's speech and language skills (96.7%); the services that are presently available to their children and how to handle their behaviour (95%); how to play and talk to my child (93.3%); techniques to use with their children at home and the selection of a communication methods (86.6%). They also expressed a need for information regarding community services, e.g. locating a doctor or therapist (80%), or educational placement (78.3%). More than 60% of participants showed a need for support from the professionals who work with their children, their child's teacher, or the therapist. Furthermore, the participants also need help to explain their child's condition to others such as siblings, other children or friends. The participants expressed less need for financial support in comparison with other needs. A total of 58.3% need help to pay for special equipment for their children, and 48.3% need help to pay for a day care and other educational services.

4.2. Summary

The results of this study indicate that participants' children were identified, fitted with hearing aids and enrolled into EI at substantially later age than the age recommended by the JCIH. Although the amount and location of intervention services were problematic for some families, the majority were satisfied with the professionals who worked with them and with the ongoing services that were provided. The statistical analysis results also showed that participants' residential area has a significant relation to timely fitting with amplification and access to EI services for participants who live outside of Riyadh. Lastly, the delivery of information emerged as a weakness in the EI system for some families.

CHAPTER FIVE

DISCUSSION OF RESULTS

5.1. Introduction

The identification of HL by UNHS aims to improve children's overall development of communicative skills. These programmes have noticeably improved the prospect for children with HL to develop aural language communication that is comparable to that of their hearing peers (Yoshinaga-Itano; 1998, Young, 2009). Without UNHS programmes, even the highest quality of pediatric care appears unable to result in the diagnosis of HL in the newborn period, or even in the first 12 months of life (Yoshinaga-Itano, 2004). However, early identification is only beneficial when quality services for the child and his or her family are implemented to take advantage of the early detection (Young, 2009; Yoshinaga-Itano, 2013). EI services have the potential to result in improved speech-language and educational development as long as appropriate and immediate intervention services are offered (Yoshinaga-Itano, 2004). UNHS is only the first step through which access to quality intervention is made available.

The data reported in the present study summarize the current state of EI services provided for children who are DFHH at two main state hospitals in Riyadh, Saudi Arabia, based on participants' perspectives toward the services delivered to them and their children. The discussion is presented based on the findings related to the sub-aims of the research.

5.2. Discussion of the results relating to sub-aim one

The first sub-aim of this study was to determine the nature of EI services provided to the parents of children who are DFHH with regards to the ages at which their children were identified with HL, hearing aid fitting, and enrolment into EI, as well as the length of delays between these services.

Unfortunately the average age at which the participant's children were diagnosed with HL in the present study was significantly late at 13.7 months, in contrast to the recommended age of three months (JCIH, 2007). This finding is also inconsistent

with the reported data of the UNHS programme in King Abdulaziz Medical City in Riyadh that children with HL have completed their audiological evaluation by four to five weeks of age, as well as an earlier study conducted in Jeddah in the western region of Saudi Arabia which reported that the average age at diagnosis of HL in children was 5.5 months (Habib, 2005). A possible reason for the delay in first diagnosis found in the current study could be the fact that the participants' children were born in a hospital where UNHS is not applied. This finding strongly correlates with previous studies which confirmed that UNHS is effective in decreasing the age at which HL diagnosed and children receive follow-up (i.e., HL confirmation, hearing aid fitting, and entry into EI) (Fitzpatrick et al., 2008; Sininger et al., 2009; Harrison, Roush & Wallace, 2003; Holte, Walker, Oleson, Spratford, Moeller, Roush & Tomblin, 2012). It is interesting to note that this study was conducted in two hospitals in Riyadh which provided hearing screening and EI services, but 68.3% of participants were from outside Riyadh which means that they did not have services in their area where there is possibly no screening for HL. Similarly, a study conducted in South Africa found that only 24% of children with HL underwent NHS after birth due to the fact that only a few hearing screening programmes were implemented around the country and mostly in urban areas (Swanepoel, 2006).

Another possible contributing reason for the late diagnosis of HL in this study is that the children with HL may be diagnosed during later childhood because of postnatal onset of HL. This was also found in previous studies which noted that the prevalence of permanent HL increased after the newborn period (Bamford, Fortnum, Bristow, Smith, Vamvakas & Davies, 2007; Watkin & Baldwin, 2011). In the current study it appears that around 35% of the participants' children have one of 11 identified risk factors outlined by the JCIH (2007); 18.3% of the participants indicated that causes of HL was hereditary, in 6.7% of cases HL was caused by maternal rubella, and in 10% HL was due to Meningitis. These risk factors are of special concern as children with HL may be screened and passed the NHS without diagnosis. For this reason, it is recommended that children who pass the NHS but have one or more risk factors should have at least one diagnostic audiology assessment again by 24 to 30 months of age and more frequent assessments may be indicated for children with a family history of HL (JCIH, 2007).

Furthermore, the consequences of HL are exacerbated for children and their families when a profound degree of HL is diagnosed (le Roux, 2014). This is a matter of concern in view of the fact that the majority of participants' children in this study (86.6%) had severe to profound HL and EI is especially critical for the development of language in this group of children (Kushalnagar, Mathur, Moreland, Napoli, Osterling, Padden, & Rathmann, 2010). Children with profound HL are known to be identified at earlier ages and therefore they also entry EI services earlier than children with less severe degrees of HL (Durieux-Smith, 2008; Fulcher, 2012). This is contrary to the present study which found that 41% of participants' children with severe to profound HL were only diagnosed after six months of age. The data analysis in this study also did not show a relationship between degree of HL and age at diagnosis, which is similar to the findings of another recent study (Spivak, Sokol, Auerbach & Gershkovich, 2009; Holte, Walker, Oleson, Spratford, Moeller, Roush & Tomblin, 2012), but contrary to earlier studies done prior to the implementation of UNHS. These earlier studies found that the age of HL diagnosis was often inversely related to the severity of HL (Coplan, 1987; Mace, Wallace, Whan & Stelmachowicz, 1991; Harrison & Roush, 1996). Note that these studies were done 25 years ago and therefore these children may not have been screened for HL. If they had screened for HL they might have been identified early, as the aims of UNHS is to lower the age at which benchmarks occur (Sininger et al., 2009).

The JCIH benchmark for fitting of amplification calls for fitting within one month of diagnosis (JCIH, 2007). In contrast to the stated benchmark, the mean age of initial fitting of hearing aids was 20 months of age. The average time lapse between diagnosis and the fitting of amplification in this study was seven months, which means that the critical period of accessing residual hearing for language acquisition is missed. The delays in providing amplification in a previous study have been attributed to financial factors (limited support from government), administrative factors (accessibility of appropriate services or services providers), and medical factors (possible chronic Otitis Media) (Harrison & Roush, 1996). Delays in the fitting of hearing aids in this study were reported by 52 of the participants (86.7%) to be the result of too long procedures and waiting periods for an appointment. The minority of participants reported that the delay was due to financial reasons (5%). The remainder of the participants (8.3%) mentioned amongst other different reasons the

distance to hospitals. These findings are in line with those from earlier reports (Coplan, 1987; Harrison & Roush, 1996; Mace et al., 1991; Prieve, Dalzell, Berg, Bradly, Cacace & Campbell, 2000). The most frequently cited reason for a delay in fitting with amplification in this study was too long procedures such as preauthorization requirements for further evaluation (Shulman et al., 2010) or delay in referral to specialists (Kasai, Fukushima, Omori, Sugaya & Ojima, 2012), and a long waiting period for an appointment for fitting with hearing aids or cochlear implant. A possible reason for this could be inadequate EI services because of the unequal distribution of services, as the services are only implemented in some hospitals around the country and mostly in urban areas such as Riyadh. Similar findings were obtained in other developing countries such as South Africa (Swanepoel, 2006). In addition, the distance from the EI centres where services are provided may be the reason why some participants indicated financial factors, as 68.3% of participants in this study travel to hospitals in Riyadh in order to obtain EI services and such travels are costly. These findings are consistent with a recent report by Limb, McManus, Fox, White and Forsman (2010) who found that families face challenges with respect to transportation for specialized services. Similar findings were reported in a study conducted in Saudi Arabia where it was found that economic factors are one of the obstacles faced by families of children with disabilities (Tamami, 2014).

Saudi Arabia faces similar challenges to other developing countries in that early detection and intervention programmes have been reported only in some hospitals and only limited numbers of families are reached (Olusanya et al., 2008).

5.3. Discussion of the results of sub-aim two

The second sub-aim of this study was to determine the participants' satisfaction with EI services provided to them and their children who are DFHH. The focus of this sub-aim was to determine the participants' satisfaction with the services provided, the time it took for the participants to find EI services and for the services to commence, as well as the number of therapy sessions.

In the current study the mean age of initial enrolment into EI service programmes was 32.7 months, which is considered relatively late compared to the recommended

age of six months as proposed by the JCIH (2007). Previous investigations have established that infants whose HL is identified before six months of age followed immediately by appropriate EI services have significantly better language abilities than those identified later (Moeller 2000; Yoshinaga-Itano, 2004; JCIH, 2007). In this study none of the participants were enrolled in an EI programme before the age of six months and the average time interval between diagnosis and intervention was 19 months. This time interval is an important predictor of intervention outcomes and demonstrates that early identification can only be effective if EI is available as early as possible, at least within the first year of life (JCIH, 2007).

Delay in intervention in this study may in part be attributed to the distance participants lived from the EI facilities, as a significant relationship was found between participants' area of residence and timely access to the intervention services. In this study, while 61.7% of all participants experienced delay and difficulty in finding a place providing intervention services, most of the participants live outside of Riyadh. The results of data analysis indicated that participants residing in Riyadh were fitted and enrolled into EI services earlier than those living outside of Riyadh. A possible reason for this finding could be that participants face challenges with respect to transportation to specialized services, particularly those who reside outside of Riyadh and have to travel long distances. This in turn may also affect the quality of services provided for them, since those who live outside of Riyadh may prefer monthly sessions to avoid transportation difficulty. In the current study 66.7% of the participants indicated that the number of therapy sessions was less than needed; once again, most of them were from outside Riyadh. Similarly, Shulman et al. (2010) found that lack of transportation can prevent families from keeping appointments with audiologists, particularly if the families must travel long distances. The finding of this study is also in line with other studies which found that the distance parents live from the EI facilities was one of the factors that impacted follow-up procedures (Spivak et al., 2009; Liu, Farrell, MacNeil, Stone & Barifield, 2008).

Another possible reason for the delay in timely access to intervention is that the primary care doctor who first contacts the family does not always have accurate information about HL or where comprehensive EI services can be obtained. In the

current study, all participants discussed their concern with a primary care doctor when they suspected that their children might have HL and 28.3% of them indicated that the first contact was not helpful in providing them with the information they needed and directing them to facilities with comprehensive EI services for their children. This finding correlates with the results of previous studies (Larsen, Muñoz, DesGeorges, Nelson & Kennedy, 2012; Munoz, Bradham & Nelson, 2011). Despite this concern, timely communication of the NHS results to the parents is essential to facilitate follow-up testing procedures (Krishnan, 2009; Moller et al., 2006). In this study 33.3% of participants expressed concern that screening results and recommendations of diagnostic evaluation were not communicated at all. Sininger et al. (2009) found that when protocols were not established for informing parents of the NHS results, delays in HL identification were similar to those for children who were not screened at all. Similarly, delays were found in the present study in the diagnosis of HL, fitting of amplification and EI enrolment. Therefore, the individual who makes the first contact with the family needs specialized knowledge and experience specific to families with children who are DFHH, in order to be able to answer their questions about HL and provide support in understanding technical concepts such as screening technologies, amplification and communication choices, and resources relevant to working with children who are DFHH (JCHI 2007). This person must also be able to direct them to facilities where they can receive comprehensive intervention services.

In addition, the delay in access to intervention may also be the result of insufficient service delivery because of lack of professionals serving the population in some regions. It is important to note that the majority of participants in this study (68.3%) came from non-urban regions (suburban, small city/town, rural area), and reported that they have to travel long distances to Riyadh to take advantage of EI services. A shortage of qualified professionals is one of the challenges facing the implementation of EI services in some regions of Saudi Arabia. Because of the lack of professionals it is difficult to expand services across the country. This correlates with a recent study which indicated that the primary barrier to follow up for families is a lack of services system capacity, which includes a shortage of sufficiently trained audiologists and inadequate EI services (Shulman et al., 2010). A main reason for the shortage of available pediatric audiologists is the limited number of university

training programmes in Saudi Arabia that emphasize pediatric audiology. Other developing countries such as Turkey face similar difficulties. It was found to be far more difficult to form an EI team and implement proper services in Turkey, particularly in rural areas, because of the lack of professionals (Bayhan & Sipal, 2011; Olusanya, 2004). Furthermore, in South Africa it was found that rural area populations presented with more delayed ages of diagnosis and intervention (Van der Spuy & Pottas, 2008), similar to the results found in the current study.

These findings are further evidence of the importance of providing EI services and establishing additional EI centres in strategic locations in Saudi Arabia, to ensure adequate and prompt EI access. The findings are consistent with results of previous studies which found that geographical location is an important barrier hindering timely access to EI services (Lai, Serraglio & Martin, 2014; Rosenberg, Zhang & Robinson, 2008; Thomas, Ellis, McLaurin, Daniels & Morrissey, 2007).

5.4. Discussion of the results of sub-aim three

The third sub-aim of this study was to determine the participants' needs regarding EI services provided to them and their children who are DFHH. Since permanent childhood HL is a lifelong condition, it brings with it long-term requirements for family support in a number of areas. The participants' perceptions relating to needs and service provision that emerged from this study can be summarized in four key discussion themes: (a) information needs, (b) need for support, (c) community services needs and (d) financial needs.

In this study, participants expressed a strong need for information on their child's speech and language development (96.7%); services available to the child and how to manage the child's behaviour (95%); techniques to use at home for their children with HL and the selection of communication methods (86.7%). This finding correlates with other previous studies reported by DesGeorges, (2003), Robinshaw and Evans (2003), and Fitzpatrick et al. (2008). Providing information to families of children with HL is of special importance particularly at the beginning of diagnosis of HL. Lack of information at this stage was reported to be one of the primary barriers to linking families to follow up (Shulman et al., 2010; Holte et al., 2012). Information gaps, according to the participants in this study, may be the result of lack of knowledge of

EI and poor communication amongst service providers. A recent study reported that many pediatricians have serious gaps in their knowledge about childhood HL because it is often not included as a part of their medical training. Because pediatricians and physicians are the first to be consulted if a HL is suspected, communication among audiologists and EHDI staff is necessary to provide ongoing information and support for physicians on topics related to EHDI (Roetto & Munoz, 2011).

Another major need of participants in this study was support from other parents. Parent contact was desired by the majority of participants (90%) and was found to be a useful component of EI programmes. Parent support groups or access to parental input seemed to fulfil several needs, including knowledge sharing, practical information about hearing devices and community resources, prognostic information, and hope. This finding is commensurate with results reported by Fitzpatrick et al. (2008). Lack of the needed family support reported in this study may also be due to service providers' lack of knowledge regarding family-to-family support services. This ignorance has been found to be a major barrier to connecting families to that form of support (Shulman et al., 2010). As a result, the key providers (hospital staff, pediatricians, audiologists, etc) need to develop new knowledge and skills related to assisting the families of children with HL (Moeller et al., 2006). Another possible reason is that these services often have insufficient funding or inadequate participation from families to make them successful. Therefore, EHDI programmes may need to reach out to other existing family support services in their area as partners in developing support programmes for families of children with HL.

The lack of community services such as those for locating a day care centre or preschool for their children was also indicated as problematic for some participants. More than two thirds (78.3%) of participants indicated that professionals of EI programmes did not make them aware of educational settings available for children with HL. This finding may also be a result of poor communication amongst service providers (Shulman et al., 2010; Holte et al., 2012). The participants in this study did not know that social service supports are generally provided by social workers or family support workers. Another possible reason is that professionals had provided the information at the time of diagnosis as part of the infant hearing programme, but

parents for one of several possible reasons had not understood or retained the information (Fitzpatrick et al., 2008). In addition, absorbing all of the information at once may be overwhelming for parents who are adjusting to the news of their child's HL (Larsen et al., 2012). Therefore, the information must be available to parents in a written format or in a resource binder so that they are able to refer to it as needed throughout the diagnostic and intervention process.

Another barrier in EI services as indicated in this study pertained primarily to financial issues. More than half of the participants (58.3%) expressed a need for funding to support the purchase of equipment such as batteries of hearing aids and replacement parts; repairs; therapy travel costs; and other services such as day care and additional therapy sessions. A similar concern was expressed by families in a study conducted by Fitzpatrick et al. (2008), who studied parents' needs following identification of childhood HL. Similar results were also reported in a study conducted in South Africa which found that parents of children with HL were in great need of financial assistance (Van der Spuy & Pottas, 2008). The lack of financial support indicated in this study may be due to the fact that financial support does not receive sufficient attention at a policy level, or is not typically viewed as part of hearing health services. This situation can be especially difficult for low-income families, as has been reported in a previous study in Saudi Arabia which found that economic factors are one of the major obstacles faced by families of children with disabilities (Tamami, 2014). Therefore, it is necessary to have policy in a place for all children with HL and their families to have access to appropriate EI services, despite financial limitations or restrictions.

5.3. Summary

Chapter Five discusses the findings regarding the status of EI services provided to children with HL, based on the perception of participants at two main state hospitals in Riyadh, Saudi Arabia. The results yielded similar findings to some other national and international studies regarding EHDI services. The results are discussed in terms of sub-aims of the research, and compared to previous research findings.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1. Introduction

Early detection and management of HL are important elements of appropriate support for DFHH children, helping them to enjoy equal opportunities in society (WHO, 2013). Health professionals in Saudi Arabia are looking forward to developing and maintaining high quality EHDI services to help all children with HL in Saudi Arabia to reach their full potential. The Joint Committee on Infant Hearing loss has provided a valuable set of guidelines and benchmarks to steer the process of EHDI programme development (JCIH, 2000). All of these guidelines are to be followed in a timely and coordinated manner in each hospital in Saudi Arabia which provides EHDI services.

It is essential that these guidelines be assessed in term of parents' perceptions regarding services for their children with HL. Parental support is a vital component of the success of EHDI (DesGeorges, 2003). It is also imperative for EHDI professionals to understand families' perceptions of the procedures in order to improve the process (DesGeorges, 2003). Establishing the perceptions of the participants (parents) in this study will facilitate the development of culturally and contextually relevant EHDI services in Saudi Arabia. In order to provide information that is culturally and contextually appropriate for parents of children with HL, it is essential to take note of what the majority of participants viewed as priority issues, and what their main concerns and needs were (DesGeorges, 2003).

The data reported in the present study describing the current status of EI services are based on parents' perceptions regarding the services provided to them and their children.

6.2. Conclusions

The main aim of this study was to determine the status of EI services provided to parents of children who are DFHH in two main state hospitals in Riyadh, Saudi Arabia, from the parents' perspective. This was achieved by the description and

discussion of the participants' responses to the questions in a semi-structured interview.

The following conclusion can be drawn in terms of the sub-aims set for this study.

Sub-aim 1 was to determine the nature of early intervention services provided to the parents of children who are DFHH.

- The results of this study revealed that although all participants suspected their children had HL at the average age of nine months, dramatic delays were reported in the diagnosis (average age of 13 months) and fitting with amplification (average age of 20 months). These ages are considered to be relatively late since the JCIH (2007) proposed that children should be diagnosed before three months of age, use of amplification should be initiated within one month of confirmation of HL, and enrollment in an EI programme should take place before six months of age.
- Most of the participants (51.7%) in this study do not know the cause of their children's HL.
- A positive aspect is that new technology hearing amplification, including hearing aids and cochlear implants, is provided to families of children with HL free of charge. However, in this study the average time delay between diagnosis and fitting of amplification seems unnecessarily long.
- Delays in the fitting of hearing aids were reported by the majority of participants in this study to be the result of too long procedures and waiting periods before an appointment was secured. The minority of participants reported that the delay was due to financial constraints and other reasons such as distance to hospitals.
- Speech/oral communication was the main method used to communicate with the majority of children in the EI programmes and at home.

Sub-aim 2 was to determine parents' perceptions regarding EI services provided to them and their children who are DFHH.

- The results of this study show that none of the participants were enrolled in an EI programme before the age of six months. The mean age of initial

enrollment into EI services programme was 32.7 months, and the average time interval between diagnosis and intervention was 19 months.

- Most of the participants (68.3%) in this study were from outside Riyadh and indicated that they have to travel long distances to obtain specialized services for their children who are DFHH.
- The majority of participants were satisfied with the professionals who work with their children and the EI services provided to them and their children. However, some of the participants face challenges in locating a centre providing comprehensive EI services, particularly those who reside outside of Riyadh.
- A significant correlation was found between participants' residence area and timely access to intervention services. Participants who reside in Riyadh were fitted and enrolled into EI services earlier than those living outside of Riyadh.
- More than half of the participants indicated that the number of therapy sessions were less than needed. Most of these respondents were from outside Riyadh. The results suggest that participants who reside outside of Riyadh face challenges with respect to transportation for specialized services, because they have to travel long distances which in turn affect the quality of services provided for them.
- More than 75% of the participants agreed that the professionals in the intervention programmes helped them to learn activities to use with their children at home, such as language activities and auditory training.
- The majority of participants (71.7%) were satisfied with the first contact when they discussed their concern with a primary care doctor. However, 28.3% of them feel that the first contact was not helpful.

Sub-aim 3 was to determine the participants' needs regarding EI services provided to them and their children who are DFHH.

- In this study, although there was a high level of satisfaction with EI services provided, the initial delivery of information emerged as a weakness in the system for some families.
- The majority of participants expressed a strong need for information on their child's speech and language development (96.7%). Participants expressed a

strong need for information on the following aspects: their child's speech and language development (96.7%); services available to the child and how to handle the child's behaviour (95%); techniques to use at home for their children with HL and selection of appropriate communication methods (86.7%).

- Parent contact was required by the majority of participants (90%) and was found to be a useful component of EI programmes.
- More than half of the participants (58.3%) expressed a need for funding to support equipment purchases such as batteries of hearing aids; replacement of parts and repairs; therapy travel costs; and other services such as paying for daycare and additional therapy sessions.
- More than two thirds (78.3%) of participants indicated that professionals of EI programmes did not inform them of educational settings available for children with HL.

6.3. Clinical implications

The results of this study have direct clinical implications for improving EHDI programmes in Saudi Arabia and for audiologists working with young children with HL and their parents. The implications include the following:

- The results showed that participants are not receiving EHDI services based on the best practice guidelines or stated benchmarks because EHDI programmes in Saudi Arabia are not grounded in defined standard guidelines. Although the international best practice guidelines will help to steer EHDI services in Saudi Arabia, it is crucial to propose guidelines fitting the unique context of Saudi Arabian order to maintain high quality services for children who are DFHH and their families.
- It is clear that the effective implementation of EHDI services in Saudi Arabia is not yet a reality for all newborns, as the HL of the majority of children in this study was first identified by their parents. Furthermore, 68.3% of the participants indicated that they have to travel long distances to obtain EI services for their children with HL.

- The need for additional EHDI centers and community based programmes was clearly demonstrated, especially in some areas in Saudi Arabia where these services are out of reach for many participants.
- This study provides an awareness of parents' perceived needs with regard to current strengths and gaps in the system. From a policy perspective, an understanding of how parents value the components of service delivery can provide insight into the most significant needs of families (Fitzpatrick, 2008). In this study, for example, the majority of the participants showed a need for essential information and support from EI services, such as help in developing their children's communication skills, information regarding community services available to their children, financial support, and other related services.
- The needs of participants who reside outside major regional centers need to be addressed.
- A shortage of qualified professionals is one of the challenges facing the implementation of EHDI services in some regions of Saudi Arabia. This study highlights the need for education and training in hearing screening procedures among other medical professionals to expand the EHDI services across Saudi Arabia.
- The vital role of the audiologist is to provide parents of children who are DFHH with all the information they need at any time and in different ways as they learn what having a HL means for their children, as well as to manage this process.
- As pediatricians and physicians usually are the first to be consulted if a HL is suspected, communication between audiologists and EHDI staff is necessary to provide ongoing information and support for physicians on topics related to EHDI.
- Family-to-family support services were required by the majority of participants. It is an important component of EI programmes, and this needs to be acknowledged when developing a Saudi Arabia protocol for EI services, because it fulfils several needs, including knowledge sharing, practical information about hearing devices and community resources, prognostic information, and hope.

- It is necessary to have a policy in place that allows all children with HL and their families to have access to appropriate EI services, despite financial limitations or restrictions.
- Generally, all information obtained from this study can be used to improve services provided to children who are DFHH and their families and to develop more effective EHDI programmes across Saudi Arabia – programmes that are culturally and contextually relevant and perhaps ultimately improve outcomes for children with HL and their families.

6.4. Critical evaluation

A critical evaluation of the research project is crucial in order to interpret the findings of the research within the framework of strengths and limitations. These are discussed below.

5.4.1. Strengths and limitations of the study

- The current study is unique in that it is the first study in the Saudi Arabia context to reflect parental perceptions regarding hospital based EI services in Riyadh provided to parents of children with HL, in the age group from infancy to 5 years.
- This investigation provided valuable information regarding weaknesses and strengths of EI services provided to the participants of children with HL in Saudi Arabia. The information can be used to improve the EI services and thereby help children to reach their full potential.
- Furthermore, this study contributes towards the knowledge in this field. Limited information is available regarding the EI services provided for families of children with HL in Saudi Arabia. This study is the first to describe the status of EI services in the context of Saudi Arabia.

This statement must, however, be tempered by some noteworthy limitations.

- Firstly, the findings are based on a questionnaire conducted in the context of a semi-structured interview. More detailed information about participants'

perceptions of their service providers could only be captured through an extensive series of interviews.

- The participant sample size was small. A larger sample size would have increased the statistical significance of this study.
- In addition, the data is based on participants' reports and thus could not be verified by clinical records.

Despite these limitations, the data provided a useful perspective on the initial stage of identification and intervention as well as insights regarding the underlying causes of delays in the EI process.

6.5. Recommendations for future research

The following recommendations are made for future studies:

- A similar study with a larger sample size may provide conclusive evidence regarding the status of EI services in Saudi Arabia,
- In order to be more culturally relevant, the sample can be taken from areas outside Riyadh, in various other regions throughout Saudi Arabia, so that the conclusions can be generalized more accurately.
- A future investigation could include the participants' perceptions regarding their children's language development after EI.
- Research can be undertaken to develop a protocol for Saudi Arabia EHDI services provided to children with HL.

6.6. Closing statement

The results of this study highlight the value of eliciting parents' perspectives on EI services that affect their child and family. It also underlines the necessity of timely follow-up of diagnosis of HL, namely fitting of amplification and enrollment in an EI programme.

In this study, participants provided valuable information regarding the EI services delivered to them and revealed a few aspects of the process of EI that need to be addressed.

This information is extremely valuable for the development of more effective EHDI programmes throughout Saudi Arabia and perhaps ultimately the attainment of improved outcomes for children with HL and their families.

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Appendix A

Letter of ethical clearance from the Research Ethical Committee



13 March 2014

Dear Prof Vinck

Project: Deaf and hard of hearing children in Saudi Arabia: status of intervention services
Researcher: HA Alyami
Supervisor: Dr M Soer
Department: Speech-Language Pathology and Audiology
Reference number: 13352751

Thank you for your response to the Committee's correspondence of 12 February 2014.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 13 March 2014. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

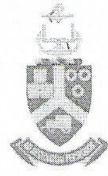
We wish you success with the project.

Sincerely

Prof. Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: karemn.harris@up.ac.za

APPENDIX B

Participants' letter of informed consent



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Speech-Language Pathology and Audiology

11 October 2013

Dear Parent,

I am a Master's student at the Department of Speech-Language Pathology and Audiology, University of Pretoria. My research project entails to determine the reported nature and effectiveness of intervention services provided to the parents of hard of hearing children in Saudi Arabian hospitals.

The research has two phases: in the first phase, parents' perspectives about early intervention services will be collected using an interview and questionnaire.

During the second phase, the communications characteristics of hard of hearing or deaf children will be assessed using four different scales of communication assessment, where specific questions are posed to the parents of these children.

The project will specifically focus on parents of hard of hearing or deaf children, aged from birth to five years old (preschool) who are identified early and start early intervention and those who did not. The information gathered could be helpful for the improvement of the intervention services provided to these children and their parents.

What will be expected from parents/ guardians?

- You as parents will be interviewed to quantify the benefits of early intervention service obtained by their child with hearing loss using structured questionnaires.
- The aim of questionnaire will be to obtain valid and reliable information from you who received early intervention services and those who did not.
- It will be expected of you to give your response on two questionnaires: first, a questionnaire of parents' perceptions about early intervention services provided for their children with hearing loss; second, questionnaire focusing on your child's language development.
- Clinical observations might be necessary to achieve more accurate scoring of language assessment scales.

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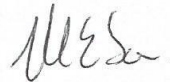
- You and your child have the right to withdraw from this study at any time without any negative consequences. All information will be treated as confidential and your name and your child's name will not be used. Data will also be destroyed should you or your child decided to withdraw from the study. Results will be published in the final thesis report, but no identifying information will be used at any time. Coded data will be stored for minimum of 15 years, in accordance with the University of Pretoria regulations.

Should you consent to participate in the project, please complete the informed- consent letter. Contact me at 0743766661 or Hudaalyami@hotmail.com should you require any additional information.

Kind Regards,

Ms Huda Alyami
Master's student

Dr Lidia Pottas
Research Supervisor



Dr Maggi Soer
Co-Supervisor

Prof Dr Bart Vinck
Head: Department of Speech-Language Pathology and Audiology

INFORMED CONSENT

Reported the nature and effectiveness of early intervention services for children with hearing loss in Saudi Arabia:

Please complete the following:

I, _____, hereby acknowledge and agree that me and my child may participate in the study outline above and consent to the data being used for research purpose. I understand the conditions as stipulated in the accompanying letter.

Signature

Date

Appendix C

Questionnaire

Please answer the questions by marking the appropriate block with a cross (x) or writing in the space provided.

SECTION A – DEMOGRAPHIC INFORMATION

Questionnaire number

For office use only

1 Date of birth of child (dd/mm/yyyy): _____

V0

A1

2 The person filling out this questionnaire is the child's

1 Mother	<input type="checkbox"/>
2 Father	<input type="checkbox"/>
3 Grandmother	<input type="checkbox"/>
4 Grandfather	<input type="checkbox"/>
5 Other (specify)	<input type="checkbox"/>

A2

3 Do you live in Riyadh? 1 Yes 2 No

A3

4 How would you describe the area where you live?

1 Large city	<input type="checkbox"/>
2 Suburban	<input type="checkbox"/>
3 Rural	<input type="checkbox"/>
4 Small city	<input type="checkbox"/>
5 Other (please specify)	<input type="checkbox"/>

A4

5 Mother's highest level of education?

1 Lower than high school	<input type="checkbox"/>
2 High school graduate	<input type="checkbox"/>
3 Diploma	<input type="checkbox"/>
4 Certificate	<input type="checkbox"/>
5 Under Graduate degree	<input type="checkbox"/>
6 Post Graduate degree	<input type="checkbox"/>
7 Other (please specify)	<input type="checkbox"/>

A5

6 Does the mother work away from home? 1 Yes 2 No

A6

8 Do you have a primary caretaker? 1 Yes 2 No

A8

9 If yes to question 8, what is the primary caretaker's highest level of education?

1 Lower than high school	<input type="checkbox"/>
2 High school graduate	<input type="checkbox"/>
3 Diploma	<input type="checkbox"/>
4 Certificate	<input type="checkbox"/>
5 Under Graduate degree	<input type="checkbox"/>
6 Post Graduate degree	<input type="checkbox"/>
7 Other (please specify)	<input type="checkbox"/>

A9

11 Father's highest level of education?

1 Lower than high school	
2 High school graduate	
3 Diploma	
4 Certificate	
5 Under Graduate degree	
6 Post Graduate degree	
5 Other (please specify)	

For office use only

A11

12 Are the parents of the child relatives?

1 Yes		2 No	
-------	--	------	--

A12

14 How many adults and children in your family live with you at home?

A14

15 Do you have any other children with hearing loss?

1 Yes		2 No	
-------	--	------	--

A15

SECTION B –QUESTIONS ABOUT CHILD’S HEARING LOSS

1 Do you know the cause of your child’s hearing loss?

1 Yes		2 No	
-------	--	------	--

B1

2 If yes to question 1, please indicate the cause of your child’s hearing loss.

1 Meningitis	
2 Maternal rubella	
3 Hereditary	
4 Premature birth	
5 Other (specify)	

B2.1
B2.2
B2.3
B2.4
B2.5

3 How would you describe your child’s degree of hearing loss?

B3

1 Mild (20–40dBHL)	
2 Moderate(40–70dBHL)	
3 Severe(70–90dBHL)	
4 Profound(90+dBHL)	
5 I do not know	

4 What type of hearing device does your child have?

B4

1 Hearing aid	
2 Cochlear implant	

For the following questions you may not know the exact age. Please answer as accurately as possible.

	Years	Months	
5 How old was your child when you suspected a hearing loss?			B5 <input type="checkbox"/>
6 How old was your child when the hearing loss was diagnosed?			B6 <input type="checkbox"/>
7 How old was your child when he/she commenced with speech therapy?			B7 <input type="checkbox"/>
8 How old was your child when he/she was fitted with hearing aids?			B8 <input type="checkbox"/>

For office use only

- 10 If there was a delay of more than three months between the identification of hearing loss and fitting of hearing aids, please describe the **main** reason of that delay.

1 Long procedures/appointment	
2 Missed appointment	
3 No finances	
4 Other (please describe)	

B10

- 11 What type of communication method is used at home? (Mark all applicable.)

1 Speech/Oral	
2 Total communication	
3 Sign/Gestures	
4 Finger spelling	
5 Other (please specify)	

B11.1
B11.2
B11.3
B11.4
B11.5

- 12 What type of communication method is used at intervention? (Mark all applicable.)

1 Speech/Oral	
2 Total communication	
3 Sign/Gestures	
4 Finger spelling	
5 Other (please specify)	

B12.1
B12.2
B12.3
B12.4
B12.5

SECTION C – INFORMATION ABOUT YOUR CHILD’S INTERVENTION PROGRAM

- 1 Has your child’s intervention program helped you to learn how to use the activity at home to develop your child’s speech and language?

1 Yes	2 No
-------	------

C1

- 2 Has your child’s intervention program helped you to learn to do auditory training activities at home?

1 Yes	2 No
-------	------

C2

- 3 Has your child’s intervention program helped you to become more aware about your child’s development and education?

1 Yes	2 No
-------	------

C3

- 4 How often does your child participate in the intervention services?

1 Once a week	
2 Twice per week	
3 Three times per week	
4 Once a month	
5 Other (please specify)	

C4

- 5 Is the amount of intervention services per month sufficient?

1 Less than needed	
2 Enough	
3 More than needed	

C5

- 6 How long has your child been involved in the intervention system?

_____ Years _____ Months

C6.1
C6.2

SECTION D – INFORMATION PROVIDED ON YOUR CHILD’S INTERVENTION PROGRAM

For office use only

Does your child's intervention program provide information about

		Yes	No		
1	The normal development of speech and language?			D1	<input type="checkbox"/>
2	The role of hearing in how children learn to talk?			D2	<input type="checkbox"/>
3	The effect of hearing loss on educational achievement.			D3	<input type="checkbox"/>
4	The different modes of communication used by persons with hearing loss?			D4	<input type="checkbox"/>
5	Educational methods and settings for children with hearing loss in your area?			D5	<input type="checkbox"/>

SECTION E – PARENTS FEEDBACK ON THE INTERVENTION SERVICES PROVIDED

		Yes	No		
1	Are the parents satisfied with the intervention services provided?			E1	<input type="checkbox"/>
2	Are there services that you feel are needed but your child is not receiving?(If yes please specify)			E2	<input type="checkbox"/>

3 Would you please rate the perceived level of the intervention service's quality.

1 Excellent	<input type="checkbox"/>	2 Very good	<input type="checkbox"/>	3 Good	<input type="checkbox"/>	4 Poor	<input type="checkbox"/>	E3	<input type="checkbox"/>
-------------	--------------------------	-------------	--------------------------	--------	--------------------------	--------	--------------------------	----	--------------------------

4 Do you have any suggestions?

SECTION F – TYPE OF CONTACT THAT THE FAMILY HAD WITH MEDICAL PROFESSIONALS WHEN FIRST CONCERNED ABOUT THEIR CHILD

1 Did you discuss your concerns with the doctor or other professionals?

1 Yes	<input type="checkbox"/>	2 No	<input type="checkbox"/>	F1	<input type="checkbox"/>
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2 How helpful was the person at that time?

1 Very helpful	<input type="checkbox"/>	2 Helpful	<input type="checkbox"/>	3 Not helpful	<input type="checkbox"/>	4 Not very helpful	<input type="checkbox"/>	F2	<input type="checkbox"/>
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SECTION G - TIME TAKEN BY PARENTS TO FIND OUT ABOUT AND RECEIVING INTERVENTION SERVICES:

1 How much time did it take you to find a place providing intervention services?

1 A lot	<input type="checkbox"/>	2 Some	<input type="checkbox"/>	3 Little	<input type="checkbox"/>	G1	<input type="checkbox"/>
---------	--------------------------	--------	--------------------------	----------	--------------------------	----	--------------------------

2 How much time did you spend to getting the services started?

1 A lot	<input type="checkbox"/>	2 Some	<input type="checkbox"/>	3 Little	<input type="checkbox"/>	G2	<input type="checkbox"/>
---------	--------------------------	--------	--------------------------	----------	--------------------------	----	--------------------------

SECTION H – THE ROLE PARENTS PLAY IN DEVELOPING A PLAN FOR SERVICES

1 Did your child's program include the development of a written therapy plan with you?

1 Yes	<input type="checkbox"/>	2 No	<input type="checkbox"/>	H1	<input type="checkbox"/>
-------	--------------------------	------	--------------------------	----	--------------------------

2 Who decided on the goals and outcomes for the child or family?

1 Mostly family	<input type="checkbox"/>	2 Mostly professionals	<input type="checkbox"/>	3 Both	<input type="checkbox"/>	H2	<input type="checkbox"/>
-----------------	--------------------------	------------------------	--------------------------	--------	--------------------------	----	--------------------------

3 Who decided on the type of services?

1 Mostly family	2 Mostly professionals	3 Both
-----------------	------------------------	--------

H3

4 Who decided on the number of sessions?

1 Mostly family	2 Mostly professionals	3 Both
-----------------	------------------------	--------

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H4

SECTION I – RATING OF INTERVENTION PROFESSIONALS

	Strongly agree	Agree	Disagree	Strongly disagree	
1	1	2	3	4	I1 <input type="checkbox"/>
2	1	2	3	4	I2 <input type="checkbox"/>
3	1	2	3	4	I3 <input type="checkbox"/>
4	1	2	3	4	I4 <input type="checkbox"/>
5	1	2	3	4	I5 <input type="checkbox"/>
6	1	2	3	4	I6 <input type="checkbox"/>
7	1	2	3	4	I7 <input type="checkbox"/>
8	1	2	3	4	I8 <input type="checkbox"/>
9	1	2	3	4	I9 <input type="checkbox"/>
10	1	2	3	4	I10 <input type="checkbox"/>

SECTION J – PARENTS’ NEEDS FOR INFORMATION

	Definitely DO NOT need help with this	Do not need help with this	Need help with this	Definitely need help with this	
1	1	2	3	4	J1 <input type="checkbox"/>
2	1	2	3	4	J2 <input type="checkbox"/>
3	1	2	3	4	J3 <input type="checkbox"/>
4	1	2	3	4	J4 <input type="checkbox"/>
5	1	2	3	4	J5 <input type="checkbox"/>
6	1	2	3	4	J6 <input type="checkbox"/>
7	1	2	3	4	J7 <input type="checkbox"/>
8	1	2	3	4	J8 <input type="checkbox"/>
9	1	2	3	4	J9 <input type="checkbox"/>

SECTION K – PARENTS’ NEEDS FOR SUPPORT

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		Definitely DO NOT need help with this	Do not need help with this	Need help with this	Definitely need help with this	
1		1	2	3	4	K1 <input type="checkbox"/>
2		1	2	3	4	K2 <input type="checkbox"/>
3		1	2	3	4	K3 <input type="checkbox"/>
4		1	2	3	4	K4 <input type="checkbox"/>

SECTION L – EXPLAINING TO OTHERS

		Definitely DO NOT need help with this	Do not need help with this	Need help with this	Definitely need help with this	
1		1	2	3	4	L1 <input type="checkbox"/>
2		1	2	3	4	L2 <input type="checkbox"/>
3		1	2	3	4	L3 <input type="checkbox"/>

SECTION M – COMMUNITY SERVICES					For office use only	
	Definitely DO NOT need help with this	Do not need help with this	Need help with this	Definitely need help with this		
	1	2	3	4		M1
	1	2	3	4		M2
	1	2	3	4	M3	
	1	2	3	4		
	1	2	3	4		
	1	2	3	4		
SECTION N – FINANCIAL NEEDS					For office use only	
	Definitely DO NOT need help with this	Do not need help with this	Need help with this	Definitely need help with this		
	1	2	3	4		N1
	1	2	3	4		N2
	1	2	3	4	N3	
	1	2	3	4		
	1	2	3	4		
	1	2	3	4		
Once again, thank you for your time.						

Appendix D

Hospital letter of Informed Consent and Permission letters from hospitals



19 September 2013

Dear Principle,

I am a Master's student at the Department of Communication Pathology, University of Pretoria. My research project entails to determine the reported nature and effectiveness of intervention services provided to the parents of hard of hearing children in Saudi Arabian hospitals.

The research will be conducted in the communication disorder clinic of the hospital. The research has two phases: during the first phase, parents' perspectives regarding early intervention services will be collected using an interview and questionnaire.

During the second phase, the communications characteristics of hard of hearing children will be assessed using four different scales of communication assessment, where specific questions are posed to the parents of these children.

The proposal will be submitted for approval to the Research Ethics Committee of the Faculty of Humanities, University of Pretoria. An informed consent letter will be sent to the hospitals involved in the research with all the details about the procedures to be followed to be approved before the research commences.

I would like to request that you consider my request to conduct my study at Hospital favourably.

Should you require any further information, feel free to contact me at 0743766661 or Hudaalyami@hotmail.com.

Kind Regards,

Ms Huda Alyami
Master's student


Dr Lidia Pottas
Research Supervisor


Dr Maggi Soer
Research co-supervisor



Please complete the following:

I _____ hereby agree to participate in the study outline above initially.

Signature

Date

Kingdom of Saudi Arabia Ministry of Health
King Fahad Medical City



(162)

IRB Registration Number with KACST, KSA: H-01-R-012
IRB Registration Number with OHRP/NIH, USA:
Approval Number Federal Wide Assurance NIH, USA:

IRB00008644
FWA00018774

October 9, 2013
IRB Log Number: 13-217E
Department: EXTERNAL
Category of Approval: EXEMPT

Dear Huda Mubarak Alyami:

I am pleased to inform you that your submission dated October 8, 2013 titled 'The reported nature and effectiveness of early intervention services for children with hearing impairment in Saudi Arabia' was reviewed and was approved.

We wish you well as you proceed with the study and request you to keep the IRB informed of the progress on a regular basis, using the IRB log number shown above.

If you have any further questions feel free to contact me.

Sincerely Yours

Prof. Omar H. Kasule
Chairman Institutional Review Board--IRB.
King Fahd Medical City, Riyadh, KSA
Tel: + 966 1 288 9999 Ext. 7540
E-mail: okasule@kfmc.med.sa





Research Office



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14571



researchoffice@ngha.med.sa

MEMORANDUM

Ref. #: RO/630/2013

Date: (G) 06 NOVEMEBR 2013

(H) 03 Muharram 1435

To: **MS. HUDA MUBARAK ALYAMI**

Principal Investigator SP13/014

Master Student

Department of Communication Pathology

University of Pretoria, Republic of South Africa

DR. JABER ALSHAMMARI

Co-Principal Investigator/Local Supervisor SP13/014

Consultant, Ear Nose & Throat

ENT Department

King Abdulaziz Medical City

National Guard Health Affairs

Subject: **SP13/014 - "The Reported Nature and Effectiveness of Early Intervention Services for Children with Hearing Impaired in Saudi Arabia"**

Thank you for submitting the above mentioned subject which was reviewed by Research Office and we have decided to **award scientific approval for this master student project sponsored by the Higher Ministry of Education in Saudi Arabia.**

Kindly be aware that you need to maintain confidentiality of information gathered from this study and not to disclose it for any purposes except for research.

Your proposal will be forwarded to the Institutional Review Board (IRB) for review on the ethical point of view and final approval. You should not start your project until this approval from IRB has been granted.

We would like to be informed upon completion, outcome and publication of your project.

APPROVED BY:

DR. MAJED AL JERAISY

Chairman, Research Committee
KAIMRC, KSAU-HS, NGHHA

Cc: Research Funding Committee, King Abdullah International Medical Research Center, NCHA

MJ/mia