

## **Title: Deaf or Hard of Hearing children in Saudi Arabia: Status of early intervention Services**

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### **Abstract:**

*Objective:* To determine the status of early intervention services provided to children who are deaf or hard of hearing and their parents/caregivers from birth to five years of age at two main state hospitals in Riyadh, Saudi Arabia, based on their parents' perceptions.

*Method:* A descriptive quantitative research design was used to determine the status of early intervention services for deaf or hard of hearing children in Saudi Arabia based on their parents' perceptions. Semistructured interviews based on a questionnaire were conducted with 60 research participants from two main state hospitals where early detection and intervention services are provided. A purposive sampling technique was employed. Descriptive and inferential statistical analyses were performed on the data collected.

*Results:* The participants' children were diagnosed at a substantially late age, resulting in delayed ages for initial hearing aid fitting and enrollment in early intervention services. A significant relationship was found between the residential area of the participants and timely access to intervention services. The results indicated that participants residing in Riyadh were fitted with hearing aids and enrolled into EI services earlier than those living outside of Riyadh. The delivery of information also emerged as a weakness in the EI system for the majority of participants.

*Conclusion:* The findings of the study suggested that limited services of detection and intervention for deaf or hard of hearing children and residential area of participants are likely to be barriers to early access to intervention services. It is proposed that the benefits of UNHS accompanied by appropriate early intervention services should be made available in all regions throughout Saudi Arabia.

Keywords: Keywords:

Age of intervention

Childhood hearing loss

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## **1. Introduction**

Hearing loss (HL) is considered one of the most prevalent disabilities worldwide. According to the World Health Organization (WHO, 2013), there are 360 million persons in the world with disabling HL (5.3% of the world's population). Of this number, 328 million (91%) are adults (183 million males, 145 million females), and 32 (9%) million are children. The majority of these cases can be treated through early diagnosis and proven intervention. Unlike in the case of many other congenital or early onset disabilities, children with HL have the prospect of developing communication skills matching their hearing peers if early identification and intervention are initiated before six months of age (Yoshinago-Itano, 2004).

Newborn and infant hearing screening (NHS) is the only way to ensure that infants with HL 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). Without systematic NHS programs, HL will only be detected after critical language development periods have passed, resulting in severely restricted prospects for literacy, and consequently academic and vocational outcomes (Olusanya, 2007). For this reason early detection of infants with HL through NHS 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 developing countries, in contrast, the detection of HL remains a passive process and occurs as a result of concerns regarding observed speech and language delays or unusual behavior (Theunissen & Swanepoel, 2008; Swanepoel, Störbeck & Friedland, 2009; Olusanya, 2004). Although the WHO encourages countries to increase prevention efforts and improve access to Early Hearing Detection and Intervention (EHDI) (WHO, 2010), very few developing countries have any systematic NHS programs. In Saudi Arabia prior to the established of the NHS program in 2010, the average age at which HL was identified was around three years and milder HL commonly remained undetected until a child had entered school (King Abdul-Aziz 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.

A pre-2010 study in Saudi Arabia indicated that the majority of people with disabilities, including Deaf/Hard of Hearing (DFHH) individuals, did not have access to psychological and educational services at an early age (Hanafi, 2007). As a result, the language and academic skills of a hearing impaired child was below average when entering school, which affected his academic achievement and progress negatively (Hanafi, 2007). Although some progress in initiating EHDI hospital- based programs has been reported in Saudi Arabia, these programs are still only reaching very limited numbers of people (Olusanya, 2008). Limited services in some hospitals have 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 early intervention (EI).

EI services is a system of coordinated services that promotes the child's age-appropriate growth and development and supports families during the critical early years. 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. 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 addition, the programme is providing on going 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).

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 conducted 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. The prevalence of HL should be assessed in various age groups in urban and rural communities, and communities with special needs (WHO, 2010). However, like in other developing countries such as South Africa (Swanepoel, 2006), NHS is implemented in only some public hospitals in Saudi Arabia, mostly in urban regions, and only limited number of people are reached.

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 the current status of EI as perceived by parents, to investigate parents' perceptions regarding EI services including delay in diagnosis, fitting, enrollment in EI services, and information provided to them and their children as well as to investigate parents' needs regarding EI services. As parent 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 parents' perspectives and to identify to what extent they feel they have benefited from the services provided.

## **2. Method**

### *2.1. Study design*

A descriptive quantitative research design was implemented in order to obtain valid information regarding the status of EI services provided to DFHH children based on their parents' perceptions in two main state hospitals in Riyadh, Saudi Arabia. The study commenced after ethical clearance was obtained from the Research and Ethical Committee of the Faculty of Humanities, University of Pretoria.

### *2.2. Study population*

The study sample consisted of 60 participants who volunteered to participate in the study, 30 from each hospital where the study was conducted, adhere to specific criteria before being eligible for inclusion in the sample. Firstly, participants had to be parents of children of DFH. Secondly, parents and their children had to have been enrolled in EI program. Thirdly, children with additional diagnosed disability 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 (Yoshinago-Itano, 2004).

The sampling methods used in this study can be described as non-probability sampling. The participants' medical records were obtained and their personal and audiological information was used to verify that they qualified for participation. The participants' educational level was high in nearly half of the sample: 43.3% (n=26) of the mothers had obtained a degree, 60% (n=36) of the fathers had a degree or higher qualification. Mothers who work away from home accounted for 33.3% (n=20) of the sample compared to 93.3% (n=56) of fathers. The majority of the participants 61.7% (n=37) were blood related, and 26.7% (n=16) of participants had other children with HL, 20% (n=12) had a second child with HL, and 6.7% (n=4) had two children with HL.

### *2.3. Procedure*

#### *2.3.1. Material and apparatus for data collection*

A semi-structured interview using a questionnaire served as data collection methods for this investigation. The questionnaire consisted of three sections. The first section aimed to determine the background and demographic information related to the participants. The second section served to investigate participants' perception regarding EI services and other related services provided. The third section was to determine participants' needs regarding EI services including: need for information, need to explain child's case to others, need for support from other parents, need for community services, and need to financial support.

The aim of the questionnaire was to obtain valid and reliable information. 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 discussion of the results and no information was omitted or distorted in order to change the outcomes of the study.

### *2.3.2. Data collection*

Data collection was conducted at two main state hospitals in Riyadh over a period of three months after permission was obtained to conduct the research at these two main state hospitals. The researcher was conducted interviews using a semi-structured interview based on a questionnaire. 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 was signed by the participants who consented to participate in the study. 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. Data collected included demographical information, and participants' perception and needs regarding intervention services and other related services.

### *2.4. Data analysis*

Quantitative data analysis was used for this study. Numerical data were obtained from the questionnaire and a list of codes was developed with codes that corresponded to each question in the questionnaire. The data were imported into Excel Microsoft to organize data 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 means and standard deviations were used to describe characteristics that were measured on a continuous scale, for example age. 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. Results**

### *3.1. Nature of early intervention services*

The results pertaining to the nature of the EI services that were received 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 are presented in Table 1.

The data in Table 1 demonstrate that the mean age at which participants suspected 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 were applied to investigate the relationship 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 Table 2.

The majority of participants from both groups were diagnosed between the age of 7 and 12 months. Nine (47.4%) of the 19 participants 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 20% (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 participants 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 participants from both groups were fitted with hearing aids when they were older than six months and only two (3.3%) were younger than six months. Ten out of 19 participants (52.6%) living in Riyadh were fitted with hearing aids at age 7-12 months, compared to only seven out of 41 participants (17.1%) living outside of Riyadh. Only two (3.3%) participants, one from each group, had hearing aids when they were younger than six months and the majority of the remaining participants (n= 8) 42.1% living in Riyadh and (n= 33) 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 the 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; 7-12 months; older than 12 months) to see whether the severity of HL resulted in earlier diagnosis. Only 11 (21.2%) of the participants who were diagnosed before six months of age had a severe to profound HL. Also, two (3.8%) of the 52 participants 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 regard 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.

### *3.2. 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 3.

More than 75% (n=45) 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 Figure 1.

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 that elapsed before commencement of services was also problematic for most of the participants from outside Riyadh. 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 statistically significant correlation was found between the two groups ( $p = 0.086$ ).

Furthermore, more than half (n=40) of the participants (66.7%) indicated that the number of therapy sessions was not sufficient (less than needed). The results in this regard are presented in Figure 2.

Figure 2 indicates that 33.3% (n=20) of participants had weekly sessions, 25% (n=15) had session twice per week, 1.7% (n=1) three times per week, 15% (n=9) had one session every month, and the remainder 25% (n=15) 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. While all

participants indicated that they discussed their concern with a primary care doctor, 28.3% (n=17) of them felt that the first contact was not helpful, while 58.3% (n=35) felt it was helpful and 13.3 % (n=8) reported that it was very helpful.

### *3.3. Participants' 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 4.

According to the data in Table 4, the majority of participants reported a need for information relating to their children's development and a need for information regarding community services. More than 60% (n=50) of participants reported a need for support from the professionals who work with their children, also need help to explain their children's condition to others such as siblings, other children, or friends. The participants expressed less need for financial support in comparison with other needs.

## **4. Discussion**

### *4.1. Nature of early intervention services*

The first objective 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, age at hearing aid fitting, and age at enrolment into EI, as well as the length of delays between these services. The average age at which the participants' 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 NHS programme in King Abdul-Aziz 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 NHS is not applied. This finding strongly correlates with previous studies which confirmed that NHS is effective in decreasing the age at which HL is 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 children with HL may be diagnosed only 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 Joint Commission on Infant Hearing (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 have been screened and passed the NHS without diagnosis. For this reason, it is recommended that children who pass the NHS but demonstrate one or more risk factor/s 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 typically enter 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% (n=25) 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 conducted prior to the implementation of NHS. 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 conducted 25 years ago and therefore these children may not have been screened for HL. If they had been screened for HL they might have been identified early, as the aims of NHS 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. In a previous study the delays in providing amplification were 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 (n=3) reported that the delay was due to financial reasons (5%). The remainder 8.3% (n=5) of the participants 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). A possible reason for a delay in fitting with amplification in this study 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% (n=41) 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 such as Nigeria (Olusanya et al., 2008), in that EI services have been reported only in some hospitals and only limited numbers of families are reached.

#### *4.2. Participants' perceptions regarding EI services*

The second objective of this study was to determine the participants' satisfaction with EI services provided to them and their children who are DFHH. The focus 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 with identification followed immediately by appropriate EI services have significantly better language abilities than those identified later (Moeller 2000; Yoshinago-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 research has demonstrated 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% (n=37) 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 the children of 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% (n=60) 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 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% (n=17) of them indicated that the first contact was not helpful in providing them with the information they needed and directing them to EI services for their children. This finding correlates with the results of previous studies (Larsen, Munoz, 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). 33.3% (n=20) 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 68.3% (n=41) 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. It is difficult to expand services across the country because of the limited number of professionals. 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 in the way of timely access to EI services (Lai, Serraglio & Martin, 2014; Rosenberg, Zhang & Robinson, 2008; Thomas, Ellis, McLaurin, Daniels & Morrissey, 2007).

#### *4.3. Participants' needs regarding early intervention services*

The third objective 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% (n=58); services available to the child and how to handle the child's behaviour 95% (n=57); techniques to use at home for their children with HL and the selection of communication methods 86.7% (n=52). 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. Communication among audiologists and EHDI staff is necessary to provide ongoing information and support for physician on topics related to EHDI, because paediatricians and physicians are the first to be consulted if a HL is suspected (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% (n=54) 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 correlates with results reported by Fitzpatrick et al. (2008). Lack of the needed family support reported in this study may also be due to services 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 lack sufficient funding or inadequate participations from families to make them successful. Therefore, providers of 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% (n=47) 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 services providers (Shulman et al., 2010; Holte et al., 2012). The participants in this study did not know that social supports services 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, 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 participants 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% (n=35) expressed a need for funding to support the purchase of equipment such as batteries for 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 a 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. Conclusion**

The results of this study indicated that participants' children were identified, fitted with hearing aids, and enrolled into EI programmes at a substantially later age than the age recommended by JCIH. Although the availability 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 participants' geographical location has a significant relationship 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 the majority of participants.

This statement is, however, tempered by some noteworthy limitations. Firstly, 58.3% of participants expressed a need for funding, other confounding demographic characteristics need to be considered when examining the relationship between timely access to EI services and geographical area of participants. Secondly, the relatively small sample of the study impact on the generalizability of the study but trends were identified that could apply to developing countries.

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## Conflict of interest

The authors declares no conflict of interest.

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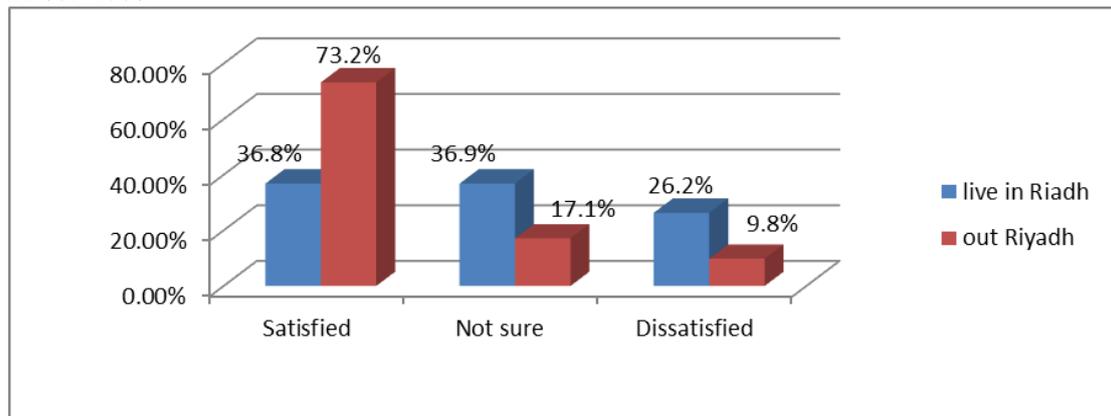
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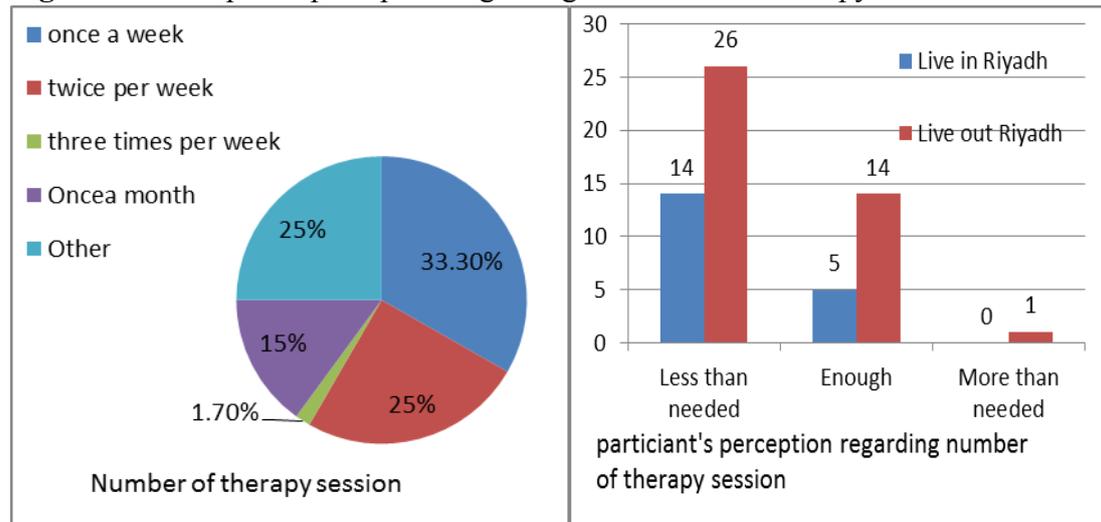
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**Figure 1:** Participants' perception of the time it took to find professionals providing EI services.



**Figure 2:** Participants' perception regarding the number of therapy sessions



**Table 1** Temporal aspects relating to diagnosis and fitting of amplification

Event	Mean age (months)	SD	Mean delay (months)	SD
HL suspected	9.3	8.3		
HL diagnosed	13.7	9.3	(HL suspected – HL diagnosed) 4	5.5
HA fitted	20.7	11.6	(HL diagnosed – HA fitted) 6.9	7.7
Intervention commenced	32.8	13.7		

**Table 2** Relationship between residence area and age of diagnosis and fitting

Residence area		Age of diagnosis (months)			Age of fitting (months)		
		0 – 6 mo	7 – 12 mo	> 12 mo	0 – 6 mo	7 – 12 mo	> 12 mo
Living in Riyadh Total = 19	Count	5	9	5	1	10	8
	%	26.30%	47.40%	26.30%	5.30%	52.60%	42.10%
Living outside of Riyadh Total = 41	Count	7	19	15	1	7	33
	%	17.10%	46.30%	36.60%	2.40%	17.10%	80.50%
Total	Count	12	28	20	2	17	41
Chi-Square Test		p = 0.616			P = 0.012 *		

\*p ≤ 0.05 statistically significant

**Table 3: Rating the perceived level of quality of EI services**

Rate	Frequency	Valid Percent
Excellent	17	28.3%
Very good	20	33.3%
Good	23	38.3%
Poor	0	0

**Table 4: 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%