

**ONLINE SURVEY ON HELP SEEKING BEHAVIOUR IN
PARENTS OF CHILDREN WITH HEARING LOSS**

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September, 2021

CERTIFICATE

This is to certify that this dissertation entitled '**Online Survey on Help Seeking Behavior in Parents of Children With Hearing Loss**' is a bonafide work submitted in part fulfillment for degree of Master of Science (Audiology) of the student Registration number: 19AUD035. This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled '**Online Survey on Help Seeking Behavior in Parents of Children With Hearing Loss**' is the result of my own study under the guidance of Dr. Sandeep M., Associate Professor, All India Institute of Speech and Hearing, Mysuru, and has not been submitted to any other University for the award of any other Diploma or Degree.

Mysuru

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Dedicated to all the things that have made me:

Dadasa, Maa, Papa and my Teachers

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Chapter 1

INTRODUCTION

Hearing loss is a ubiquitous communication disorder, with a staggering global prevalence of 5% (WHO, 2011). This amounts to around 466 million individuals, across the world, and a good proportion of this is reported in the paediatric population. Of the reported childhood onset hearing loss, the prevalence of congenital hearing loss is 1.33 per 1000 live births and the prevalence of hearing loss in school going children is 2.83 per 1000 children (Korver et al., 2017). In India, the prevalence of hearing loss is estimated to be 6.3%, with 7.6 % adult-onset hearing loss and 2% childhood onset hearing loss (WHO, 2018).

Individuals with hearing loss, irrespective of the age of onset of hearing loss, experience difficulty in speech recognition and communication. Hearing loss also has negative impact on the individual's physical, social, cognitive and economic well-being (Hornsby, 2013; McGarrigle et al., 2014; Nachtegaal et al., 2009). It is therefore a debilitating condition, and early identification as well as early intervention of hearing loss are crucial to minimize the negative influence.

Despite the disconcerting impact of hearing loss, it is seen that only a small percentage of individuals with hearing loss seek help for their hearing difficulty (Barnett et al., 2017), and only a subset of this population accept the rehabilitative measures prescribed for them (Barnett et al., 2017; Cohen et al., 2005; Davis et al., 2007). The action of seeking help from an individual or health care services while encountering a difficult situation is called *Help seeking Behaviour* (HSB) of an individual (Rickwood and Thomas, 2012). Therefore, it may be stated that individuals with hearing loss exhibit poor HSB. Understanding the reasons for poor HSB may help to reach out to individuals with hearing loss. This may minimize the impact of

hearing loss on them and their significant others. One efficient way to improve the hearing HSB is to study the factors that influence the HSB in individuals with hearing loss.

Several studies have explored the HSB in adults and the elderly (Abdellaoui & Tran Ba Huy, 2013; Barnett et al., 2018; Knudsen, Öberg, Nielsen, Naylor, & Kramer, 2010; S. Kochkin, 2009; Kochkin, 2007; Laplante-Lévesque, Hickson, & Worrall, 2010, 2011). Multiple factors have been reported to influence the HSB in them, which may be divided into barriers (reasons for not approaching a hearing health professional), motivators (factors that positively influence someone to seek help), and compliance factors (reasons someone follows the recommendations and continues to access help).

Examples of barriers to access hearing health care include less perceived hearing loss (Kochkin, 2007; Laplante-Lévesque et al., 2010; Öberg, Marcusson, Ngga, & Wressle, 2012), poor access to hearing health care, inconvenience (Laplante-Lévesque et al., 2010a), non-referral from primary care physicians (Schulz, Modeste, Lee, Roberts, Gabrielle, et al., 2016), poor socio economic status (Abdellaoui & Tran Ba Huy, 2013a; Laplante-Lévesque et al., 2012; Meister et al., 2008, 2014), and not having hearing tested (Kochkin, 2007). On the contrary, factors that motivate individuals to seek help for hearing loss include severe degree of hearing loss, longer duration of hearing loss, high perceived hearing loss, difficulty understanding speech (Claesen & Pryce, 2012a; Duijvestijn et al., 2003; Meyer et al., 2014; Swan & Gatehouse, 1990; Van den Brink et al., 1996), self-motivation, good referral sources, positive attitude and family support (Abdellaoui & Tran Ba Huy, 2013a; Claesen & Pryce, 2012a; Duijvestijn et al., 2003; Van den Brink et al., 1996). Examples of compliance factors include an individual's satisfaction with the services as well as the

hearing device (Cox et al., 2005), and realistic expectations from rehabilitation services (Bille & Parving, 2003a).

The aim of learning about the factors influencing the HSB is to improve it, so that more individuals can benefit from the hearing health care services. However, a simple classification of the observed factors may not be sufficient to do that. The solution is to implement a predictive model for hearing health care, like the Health Belief Model (HBM) (Hochbaum, 1958; Rosenstock, 1974). Such a model would predict the possible hearing health behaviour of an individual, depending upon the different factors considered. It might also be able to predict what changes in the studied factors can change the HSB.

The HBM explains the HSB in individuals using 6 different constructs. It states that HSB is influenced by their perceived susceptibility (the likelihood of them developing a hearing loss), perceived severity (their experience of hearing loss), perceived self-efficacy (their perception of their ability to pursue the treatment), perceived benefits (their expectations about the outcome from treatment/rehabilitation), cues to action (factors that motivate them to seek help) and perceived barriers (their experience of difficulties to access treatment) (Champion & Skinner, 2008; Glanz et al., 2005). This model has been effectively used to understand the HSB in individuals with hearing loss (Saunders et al., 2013; Van den Brink et al., 1996). Studies have been successfully carried out based on HBM, exploring the HSB in hearing health care, using questionnaires. Van den Brink et al. (1996) used a questionnaire developed based on the HBM and were able to differentiate hearing aid users and non-users using the same. Saunders et al. (2013) developed the Hearing Beliefs Questionnaire (HBQ), which is a 26-item questionnaire with 6 subscales (the constructs of HBM). They were able to classify individuals' hearing help seeking behaviour based on this questionnaire.

1.1 Justification for the Study

The impact of hearing loss is more pronounced in paediatric population, affecting the child's linguistic, social and cognitive development (Stevenson et al., 2011), if not addressed early. Early identification and rehabilitation of hearing loss is crucial for effective rehabilitation of children, and to ensure normal speech and language, cognitive, and social development. In the Indian scenario, 4 out of every 10000 babies born experience profound hearing loss (Garg et al., 2009). The average age of identification of hearing loss in the country is reported to be 2-4 years (Varshney, 2016). Despite this, a universal new-born hearing screening program does not exist in the country at the national level. This shows a strong need to improve the help-seeking behaviour for hearing loss in the paediatric population in the country.

To study the HSB in paediatric rehabilitation is to study the HSB of the parents of the concerned children. The factors identified from studies carried out in the adult and the elderly population may not be applicable to the paediatric population, because- (1) the decision making process in this case is to be made by the parent of the child instead of the child herself/himself; (2) their decision will be influenced by the parents' exposure and knowledge about the impact of hearing loss on the overall development of the child.

Multiple factors might influence early identification and rehabilitation of hearing loss in children (JCIH, 2019). New born hearing screening helps in early identification and rehabilitation of hearing loss in young children. The information provided to parents, the parents' perception of assistive technology for hearing, the attitude of professionals and educational authorities, the quality and availability of support system will all influence the rehabilitation choices in parents (Elveke, 2000). There are also other factors such as the age of the child, the magnitude of hearing loss,

exposure to other family members with hearing loss, the parents' attitude and knowledge about hearing loss, information received from professionals, family and friends, parents' personal values and the belief about hearing loss, their expectation for their children, and availability of services in schools and close to home that influence their choice of rehabilitation (Yeulin Li et al., 2003; Bruin & Nevøy, 2014; Crowe, McLeod, et al., 2014; Guiberson, 2013; Decker et al., 2012).

However, the factors identified from studies carried out in other countries may not be applicable to the paediatric population in India, due to differences in (1) the socio-economic status (Rosengren et al., 2019), (2) the health care facilities and access to them (WHO, 2013), (3) the population-to-professional ratio (WHO, 2009), and (4) literacy rate of the countries in which the previous studies were conducted (Grupe & Rose, 2010). Further, most of the studies assessing HSB in the pediatric population have focussed on the factors that influence the rehabilitation choices among the parents, rather than the assessment of hearing loss. Considering that the mean age of identification of hearing loss in India is between 2-4 years (Varshney, 2016), it is imperative that we study the factors that influence the parents HSB leading to the assessment of their child's hearing loss.

In India, the factors such as socioeconomic status, level of education, geographical location, cultural background, and access to resources are all reported to be barriers to seeking help for hearing difficulties in parents of children aged between 5 to 15 years (Patel et al., 2014). In southern Indian the barriers observed are failure to recognise deafness, the dominant role of elders in household decisions, belief that deafness would resolve, reassurance from a child's overall good health, lack of funds, and transportation barriers to reach the center, particularly from rural areas, also were barriers to accessing hearing services (Merugumala et al., 2017).

As seen above, the literature shows scattered studies that examined parents' approach to rehabilitation choices. However, no study has examined the HSB in parents of children with hearing loss systematically, and as a whole within the framework of a predictive model of help seeking. A study that assesses the HSB in parents of children with hearing loss for the assessment of hearing loss is the need of the hour. Hence the present study aimed to assess the HSB of parents of children with hearing loss through a questionnaire.

1.2 Objectives of the Study

The objectives of the study are to

1. Develop an online questionnaire to assess help seeking behaviours in parents of children with hearing loss.
2. Check the reliability of the developed questionnaire.
3. Administer questionnaire on parents of children with hearing loss and analyse the responses.

Chapter 2

REVIEW OF LITERATURE

Help-seeking behaviour (HSB) is defined as any action of voluntarily seeking help from the health care services or from trusted people in the community for understanding, guidance, treatment, and general support when feeling in trouble or encountering stressful circumstances (Rickwood & Thomas, 2012). Several factors influence HSB in individuals with hearing loss. This chapter reports the literature relevant to HSB under the following headings:

1. Factors affecting Help Seeking Behaviour (HSB)
2. Hearing Help Seeking Behaviour in Parents of Children with Hearing Loss
3. The Health Belief Model (HBM)
4. Hearing Help Seeking Behaviour in parents of children with hearing loss in India

2.1. Factors affecting Help Seeking Behaviour (HSB)

There are several factors that affect HSB. These factors may be divided into barriers, motivators, and compliance factors. In the context of hearing loss, ‘Barriers’ are those factors that stop an individual from approaching health professionals for hearing difficulties, while ‘Motivators’ are those factors that motivate them to approach health professionals for hearing difficulties. ‘Compliance factors’ ensure that these individuals continue to access the support provided and utilize the solutions recommended for their hearing difficulties. All these factors together will help us better understand the HSB of individuals with hearing loss.

Barriers: There are audiological (like degree of hearing loss) and non-

audiological factors (like financial status) that are reported in the literature as barriers to access hearing health care services. The studies reported below have been mostly carried out to understand the barriers to uptake of hearing devices in the participants.

An extensive survey was carried out by (Kochkin, 2007a) among 2057 hearing aid users and 2169 non-hearing aid users to understand the variables that influence the uptake of hearing aid in hearing impaired population. The study reported the participants' attitude towards wearing hearing aids, perception of the efficacy and value of hearing aids, perceptions of the appearance of people with hearing aids, internal and external stigma, hearing loss coping mechanisms, communication with others, stress associated with hearing loss, severity of hearing loss, social comparison, anger prevalence, depressive feeling because of hearing loss, societal pressure, professional opinions, support network opinions, physical health, and financial situation of family, among other factors. It was observed that a more significant percentage of individuals in the group of non-hearing aid users perceived their hearing loss to be mild (39%) or moderate (48%) in degree. Only around 14% of individuals in this group perceived their hearing loss to be severe to profound in degree. In the hearing aid user group, 39% of the individuals perceived their hearing loss to be severe to profound in degree.

Laplante-Lévesque et al. (2010) reported decision-making for hearing loss in elderly individuals with hearing loss. They found that individuals with lesser perceived hearing loss did not prefer audiological rehabilitation. Around 70% of the participants of the study had degrees of hearing loss equal to or less than mild. In general, individuals with lesser degree of hearing loss or lesser perceived hearing loss tended to deny the impairment. They also found that individuals sought help for their hearing loss based on the availability of services with regard to the location, flexibility

in timing, and the ease of access.

Another commonly reported factor that decides an individual's decision to access and use hearing aids is their socio-economic status (Abdellaoui & Tran Ba Huy, 2013a; Laplante-Lévesque et al., 2012). Individuals with poor socio-economic status were less likely to pursue hearing rehabilitation.

Non-referral from primary care physicians is also a barrier for help-seeking for hearing impairment (Schulz, Modeste, Lee, Roberts, Saunders, et al., 2016). A survey of 601 elderly individuals to study their use of hearing aids found that individuals who tested between 1- 4 years were more likely to use hearing aids than individuals who got tested after 5-9 years of age (Bainbridge & Ramachandran, 2014). Therefore, failure to undergo hearing testing and the time at which their hearing was tested were reported to influence the willingness of individuals to seek hearing healthcare for rehabilitation. In the MarkeTrak VII survey report, Kochkin (2007) reported that 40% of 2169 non-hearing aid users did not purchase hearing aids because they did not undergo hearing testing. He also reported that around 20% of non-hearing aid users were ignorant about getting their hearing tested.

Motivators: Motivators are the audiological or non-audiological factors that positively influence an individual to access hearing healthcare. Higher degree of hearing loss, increased duration of hearing loss, perceived hearing difficulty, and difficulty in understanding speech are examples of audiological factors (Claesen & Pryce, 2012b; Duijvestijn et al., 2003; Meyer et al., 2014; Van den Brink et al., 1996) that are reported as motivators, whereas self-motivation, attitude, and family support are examples of non-audiological factors (Abdellaoui & Tran Ba Huy, 2013b).

Laplante-Lévesque et al. (2010b) carried out a study using shared decision-making and semi-structured interviews to decide the preferred intervention in 22

participants. Popelka et al., (1998) surveyed 1629 individuals with hearing loss, to understand their reasons for accessing hearing health care. Both studies found that an individual's recognition of and acceptance of their hearing impairment are motivators to seek intervention

Abdellaoui and Tran Ba Huy (2013) surveyed 184 adults with hearing loss in France. Around 2/3rd of the participants reported that they were recommended by ENT surgeons to seek audiological services. This indicates that referral for hearing testing as well as the referral sources serve as motivators for individuals to access audiological services.

Meyer et al. (2014) collected data on several audiological and non-audiological factors from 307 people aged 60 years and above. The factors studied included dexterity, significant life events, attitude towards hearing aid questionnaire, among others. They also obtained the participants' audiological information retrospectively, and administered questionnaires like the Hearing Handicap Questionnaire. Multivariate, multinomial logistic regression models were fitted to the collected data in order to identify the factors associated with Hearing Impairment consultation and hearing aid uptake by the participants. The study found a positive attitude towards hearing aids, individual's ability to handle hearing aid's controls independently, support by significant others, prompt by another person's, perception of activity limitation, a higher degree of hearing loss in the better ear, and poor reasoning skills to be positively associated with an individual's decision to get a hearing assessed.

An individual's perception of benefit from approaching help is an essential motivating factor (Van den Brink et al., 1996). They found individuals' attitudes concerning hearing loss and perceived benefit from the hearing aid to impact the help-

seeking behaviour, with a positive approach favouring help-seeking. Also, if an individual is ready to take responsibility for a communication breakdown due to hearing loss, he/she is more likely to seek help for the problem. This attitude will also mean that the individual accepts the opinions of other communication partners and will amend the approach to cope with the situation (Claesen & Pryce, 2012b).

Cox et al. (2005) extensively analysed the personality traits of 230 individuals with hearing loss who approached hearing assessment to find a solution to their problem. These individuals were more pragmatic and systematic and were willing to learn the technology necessary to use a hearing aid. They also perceived more psychological strain and were ready to seek help for the same. Apart from these factors specifically pertaining to the individual and the professionals, factors such as support from family also are reported as motivators. For example, through a structured interview of 1419 participants aged 55 years or more, Duijvestijn et al. (2003) found that support from their families and acquaintances is an important motivator.

Audiological factors serving as Motivators are reported by a number of studies. Individuals with greater degree of hearing loss and longer duration of hearing loss are reported to be more likely to access hearing health care (Van den Brink et al., 1996). Individuals with more trouble understanding speech in noisy environments and those with difficulty understanding speech from the television were more willing to seek audiological help (Abdellaoui & Tran Ba Huy, 2013b; Kochkin, 2009). A person's impression of activity constraint as a result of hearing impairment was also a common motivator (Duijvestijn et al., 2003; Kochkin, 2007a; Meyer et al., 2014; Van den Brink et al., 1996). Palmer et al. (2009), found that individuals who perceived higher severity of hearing loss had more positive help-seeking behaviour.

Compliance Factors: Compliance factors decide an individuals' acceptance of recommendations made by hearing health professionals. Multiple compliance factors are reported in the literature for hearing care. Cox et al. (2005) administered an inventory and some other rating scales on 230 individuals with hearing loss where different non-audiological factors deciding acceptance of hearing aids were assessed. The individual's satisfaction with the care and services provided was reported as an essential factor that decides his/her compliance. Grutters et al. (2008) analysed responses of 150 individuals with hearing loss to questionnaires tapping compliance factors and found that sustained and efficient services from a private practitioner are preferred by most individuals. Using the Hearing Aid Ownership Inventory, Bille and Parving (2003) observed a correlation between realistic expectations from hearing assessment and intervention and the rehabilitation outcome. They observed that an individual's continued use of hearing aids is influenced by their perception of benefit from the hearing aid, their perception of handicap from the hearing difficulty, their perception of self-efficacy, and the attitude and support from family. Individuals should also have realistic expectations from the hearing testing and hearing aids to continue using the hearing aid. Also, literature reports that receiving free hearing aids without a positive attitude towards using hearing aids does not act as a compliance factor (Meyer et al., 2014). Motivation, too, is a critical compliance factor (Hickson et al., 2014).

2.2 Hearing Help Seeking Behaviour in Parents of Children with Hearing Loss

Hearing help seeking behaviour among parents of children with hearing loss has not been extensively studied. Studies have explored the existence and efficacy of early hearing detection and intervention programs and awareness about hearing loss, its consequences in children with hearing loss, and the treatment options.

Bush et al. (2014) aimed to investigate the incidence of congenital hearing loss, and delays and disparities in the diagnostic process in Kentucky. They reported that 19 % of children who failed the initial screening procedure could not obtain follow-up to diagnose hearing status. They reported that geographical location influences the rate of follow up to diagnose hearing loss.

Alyami et al. (2016) determined the status of early intervention services provided to children who are deaf or hard of hearing the parents/caregiver's perceptions regarding early intervention services including delay in diagnosis, fitting, and enrolment in early intervention services. They also collected information regarding the details provided to them and their children during counselling sessions. The result showed that the average age of suspicion was nine months and the average age for a diagnosis was 13.3 months. For hearing aid fitting, the mean age was 20.2 months. In their study participants, the delay in the fitting of hearing aid resulted from the lengthy procedure and longer waiting for appointments.

The level of parental awareness of childhood hearing impairment and its relationship to access, and use of ambulatory health services for ear care were studied by Omondi et al. (2007). They reported that most parents are aware of their children's hearing loss, but that they detect them late. Also, the parents' level of hearing care service demands and uptake were observed to be deficient.

Elpers et al. (2016) qualitatively assessed the perspectives and experiences of rural parents/guardians in the Appalachian region of Kentucky on infant hearing healthcare. They had accessed the early hearing detection and intervention system following a failed *new-born hearing screening* (NHS) test. Many participants reported that they did not receive results from NHS while at the hospital. They received the results after 2-3 weeks of the testing, or via mail which they did not understand. They

reported that these reasons lead to delayed diagnosis in their children. Several participants reported that recommendations for child's hearing care from the paediatrician or primary care provider were not made. Travel distance and transportation were concerns for most of the participants who were from a rural area. Financial constraints led to delayed diagnosis and intervention. Other reasons such as insurance coverage delays, knowledge about hearing healthcare, and willingness to seek help also influenced the age of diagnosis and intervention.

Questionnaire-based surveys revealed that a range of factors influenced parental decisions, including advice and information received from professionals, family, and friends (Bruin & Nevøy, 2014; Crowe, Fordham, et al., 2014; Decker et al., 2012; Li et al., 2003), characteristics of the child's hearing loss (Crowe, McLeod, et al., 2014; Li et al., 2003), expectations for their children (Crowe, Fordham, et al., 2014; Crowe, McLeod, et al., 2014; Li et al., 2003) practical communication needs (Crowe, Fordham, et al., 2014), availability of services in schools, proximity of services to home (Guiberson, 2013; Li et al., 2003), personal judgment and values or views about deafness (Decker et al., 2012).

The *Longitudinal Outcome of Children with Hearing Impairment* (LOCHI) study was done to explore the factors influencing parents' choice of communication mode during early education of their child with hearing loss (Scarinci et al., 2018). The results showed that parents require unbiased, descriptive information and assessment results from an audiologist so that they can consider all options while deciding for their child. They also required continual support to carry out their choices as they adjust to their children's changing needs.

2.3 The Health Belief Model

Studies have used the Health Belief model (HBM) to understand the hearing HSB in individuals with hearing loss. Van den Brink et al. (1996) tried to investigate hearing help-seeking behaviour in elderly individuals. He tried to explore the differences in attitude in other groups showing dissimilar help-seeking behaviour. Six hundred twenty-four elderly individuals were selected for studying help-seeking behaviour. The hearing assessment was done using pure tone audiometry. The help-seeking evaluation was done using a questionnaire along with a hearing handicap and disability inventory. The attitude of individuals was assessed using a questionnaire (41 questions) based on the HBM. After the influence of hearing impairment was controlled, the authors tried to study the relationship between help-seeking and attitude. Non-consultants who did not visit a physician for their hearing loss perceived their hearing loss due to aging and most frequently showed passive acceptance of hearing loss. Those who consulted physicians for their hearing loss did not take hearing aid because of stigma-related barriers to hearing aid use. Moreover, those who were currently using hearing aid had a favourable attitude towards hearing aid.

Saunders et al. (2013) studied the help seeking behaviour in adults. HBM was used to develop the questionnaire as its constructs were deemed to be more relevant to hearing-related issues. The authors' initial Hearing belief questionnaire (HBQ) had 60 statements and a 10-point rating scale. Individuals ranging from 18 to 89 were included in the study. Along with the questionnaire, demographic details such as gender, hearing loss, veteran, hearing testing, and hearing aid usage were collected from the participants. After removing the questions that resulted in floor and ceiling effects, 26 questions remained in the final questionnaire. With the answers to the Hearing Belief questionnaire, the authors were able to divide the respondents into

early and late hearing help seekers.

Investigations were carried out to modify and enhance HBM to include the perceived burden of hearing loss on communication partners. Four hundred thirteen participants completed three validated questionnaires. The perceived burden of hearing loss on communication partners was a significant predictor of the subjects' hearing evaluation and help-seeking behaviour, and the authors recommended including this factor to strengthen the Heath Belief Model (Schulz, Modeste, Lee, Roberts, Saunders, et al., 2016).

2.4 Hearing Help Seeking Behaviour in parents of children with hearing loss in India

A couple of studies have explored the factors that influence hearing health care services in India. Patel et al. (2014) studied the factors that influenced parental decision making to seek help for hearing and ear-related difficulties from individuals who sought help at an ENT clinic. They observed late access to hearing health care and reported that a lack of hearing health services and the absence of new-born hearing screening programs must undoubtedly influence parents of children with hearing loss's willingness to seek care. Apart from this, various other factors such as their socioeconomic status, level of education, geographic location, cultural background, and access to resources may all have an impact (Patel et al., 2014)

Study done by Merugumala et al. (2017) explored the barriers to hearing health care in pediatric population (especially of the lower economic status) in Southern India through interviews. They reported that failure to recognise deafness, the dominant role of elders in household decisions, belief that deafness would resolve, reassurance from a child's overall good health, lack of funds, and transportation barriers to reach the centre, particularly from rural areas, also were barriers to

accessing hearing services. Educational, cultural, navigational, and financial barriers to receiving adequate hearing health services exist prior to diagnosis, especially for those of lower socioeconomic status and residents of rural areas. They also observed that word of mouth was a common way for parents to hear about services.

This chapter reports the available literature relevant to the HSB observed in adults and parents of children with hearing loss. Studies discussed the HSB under different factors, namely barriers, motivators and compliance factors. Major barriers in adults with hearing loss were negative attitudes and stigma towards hearing loss and hearing aids, financial constraints to access hearing health care, non-referral from physicians and many more. Similarly, in parents of children with hearing loss, lack of awareness on hearing loss, financial constraints, age of child, lengthy procedures and longer waiting period for hearing assessment and rehabilitation, and lack of access to hearing health care are found to be major barriers. Self-motivation, family support, higher degree of hearing loss, and positive attitude towards hearing loss and hearing aids are found to be some of the motivators in adults with hearing loss. Realistic expectations from hearing testing and hearing aids, and sustained and efficient services from practitioners constitute major compliance factors in adults. A couple of the studies have used the HBM to understand the hearing HSB in individuals with hearing loss, in the adult population. Indian studies on Help seeking Behaviour in parents of children with hearing loss have focused on understanding the barriers to seek help.

Chapter 3

METHODS

The study was carried out in two phases. During the first phase, a questionnaire based on the constructs of the Health Belief Model (HBM) was developed and validated. The questionnaire was developed to understand the factors that influence the help-seeking behaviour (HSB) in parents of children with congenital hearing loss. In the second phase of the study, the questionnaire was administered to parents of children with hearing loss to assess the reliability of the developed questionnaire. A survey design was used to verify the proposed objectives of the study. The details of the methods followed are given in the subsequent sections.

3.1. Phase I: Development of the Questionnaire

3.1.1. Literature search and derivation of factors related to hearing loss

A thorough review of the existing literature about the barriers, motivators, and compliance factors related to the hearing HSB was carried out. This search included studies on the older individual with hearing loss and parents of children with hearing loss. A number of factors were derived from this search. In addition to the factors derived from the literature search, certain factors that were deemed important by experts in the field of audiology were also included. These factors were used to frame the questions under the six constructs of the HBM, namely:

- *Perceived susceptibility*: the feeling of being vulnerable to a condition and the extent to which the individual believes that he or she is at risk of acquiring the condition (hearing loss in this situation).
- *Perceived severity*: the feeling of seriousness of the condition and the consequences incurred if affected by the condition (medically and socially)

- *Perceived benefits*: the belief that intervention will benefit the child
- *Perceived barriers*: the difficulties an individual believes that she needs to overcome in order to effectively access intervention
- *Perceived self-efficacy*: the individual's belief in his or her ability to use and gain benefit from the intervention
- *Cues to action*: factors that prompt an individual to take action (internal, or external)

3.1.2. Construction of the questionnaire

Using the factors that influence hearing HSB derived from the literature review and discussions with experts in the field of audiology, a questionnaire was developed in English. The questionnaire was constructed following the theoretical model of HBM and the developed questionnaire was arranged under 6 constructs of the model

Format of the questions and structures of the questionnaire: The questionnaire was constructed in the form of statements. The guidelines recommended by Lee (2006) were followed while framing the statements, ensuring that the questionnaire used simple vocabulary and comprehensible, unambiguous statements. It was ensured that there were at least three statements under each construct of the HBM. The response expected for each statement was 'Agree', 'Not sure', or 'Disagree' resulting in 3-point scale with a scoring pattern of 3, 2, or 1 respectively. Statements with reverse scoring were included as catch trials. Two such statements were included- one each under constructs 1 (Perceived susceptibility) and 4 (Perceived benefits). Additionally, three questions assessing the parent's awareness about the hearing loss and its consequences and their accessibility to hearing health care were also included in the questionnaire with expected answer of yes/no. The developed questionnaire was implemented as a

Google form for administration on the prospective respondents.

Review and Revision of initial pool of questions: The developed questionnaire was given to three experts in the field of auditory rehabilitation and to three laypeople randomly selected, who could read and understand English for validation. The questionnaire was assessed for its content and face validity. Professionals in the field of Audiology rated the statements based on the content, meaning, accuracy, context, and clarity of meaning on a two-point rating scale (yes/no). They were also asked to judge if the statements fell into the construct of HBM they were grouped under, and whether the statements conveyed the intended meaning in neutral emotion. The suggestions made by the three experts were implemented and the final format of the questionnaire was set. The three laypeople were asked to rate statements for their readability, clarity of meaning, and ease of understanding on a two-point rating scale (yes/no). The readability of the statements was assessed by them on the Google form where they judged the font, type and colour. The suggestions made by them were implemented and final format of the questionnaire was prepared.

3.2 Phase II- Administration of the Questionnaire on Target Population

In the second phase, the developed questionnaire was administered on the target population. Along with their response to the developed questionnaire in the Google forms, demographic details regarding the parent and the child were collected from the participants. Five audiological and non-audiological factors each related to the child and their HSB were also collected from the participants (Table 3.1).

3.2.1 Participants

Thirty-eight adults who were parents of children with hearing loss took part in the study. They had sought hearing assessment for their child at a private or

government administered speech and hearing institute/clinic in India. The participants' children had bilateral sensorineural hearing loss and were either using or not using hearing aids. All the participants who had reading comprehension of English and had access to the internet were selected for data collection. Parents of children with associated problems and unilateral hearing loss were excluded.

Of the 38 individuals who took part in the study, 9 were males and 29 were females. The mean age of the participants was 35.68 years (age range: 23-63 years). In the families of the participants, the father had completed educational level of Primary (1), Secondary (6), Higher Secondary (11), Graduation (14), or Post-graduation (6). Similarly, the mother had completed the educational level of Primary (1), Secondary (5), Higher Secondary (11), Graduation (17), or Post-graduation (6). Most of the mothers (30) were home-makers, and some of them were employed in teaching, law, and medical sectors (8). Among the fathers, 15 were working in private sector and 5 were government employees, and 18 were having their own business. Among the participants 6 were aware and 32 were not aware of hearing loss and its consequences; 24 participants had and 14 participants did not have hearing healthcare services available at their place.

The mean age of their children was 7 years 8 months. The mean age of onset, detection and initial diagnosis of hearing loss was 1 year 3 months, 1 year 6 months, and 1 year 8 months respectively. Only 9 out of 38 children had their initial hearing screening done at birth. Almost 25 of the children had profound degree of hearing loss. Around 9 of the children had severe degree of hearing loss and 2 of the children had moderate and moderately severe degree of hearing loss.

3.2.2. Procedure

Information regarding the prospective respondents (parents of children with

hearing loss) was taken from audiologists working in different sectors across different states of the country and from patient case files at the department of Clinical services, AIISH, Mysuru. The questionnaire developed in the first phase of the study, implemented in Google forms was sent to the parents via e-mail ID or WhatsApp contact and the responses were collected. Prior informed consent was taken before collecting data from all the participants for their participation in the study. Information regarding the study along with instructions for respondents was included in the form. Instructions given were as follows:

“The following Questionnaire has SIX KEY STATEMENTS. Under each statement, a column shows the probable responses. You are requested to read the statements carefully and mark your choice (Agree, Disagree, or Not sure) against each possible response. Your choice should be based solely on your experience as a parent of a child with hearing loss before the child’s hearing loss was diagnosed”.

The demographic details and the details regarding the audiological and non-audiological factors were also collected along with the questionnaire.

Table 3.1: *Details of the audiological and non-audiological factors collected from the participants*

Audiological factors	Non-audiological factors
Age of onset of hearing loss as reported.	Literacy level of the parents.
Age of detection of hearing loss.	Socio-economic status of the parents.
Information on neonatal hearing screening.	Awareness about hearing disorders and hearing health services.
Age of initial diagnostic audiological assessment.	Geographical location.
Degree of hearing loss and other test results as per the initial audiological assessment.	Availability of hearing health services.

3.2.3. Statistical analysis

All statistical analyses were conducted using Statistical Package for the Social Sciences (SPSS) v21. Internal consistency of the questionnaire of the questionnaire was evaluated by assessing the reliability using the Cronbach Alpha coefficient. Cronbach's alpha was calculated for each construct after obtaining the participant's responses. Apart from the reliability analysis, the relationship between help seeking behaviour questionnaire score and audiological and non-audiological factors was assessed in the following manner.

Responses obtained for the following three questions- 'Did you have hearing healthcare service available at your place?', 'Were you aware of hearing loss and hearing health services before the child was born?' and 'Was hearing screening done at birth?' were obtained from the participants. For each of the three questions, individuals who responded 'yes' and individuals who responded 'no' were divided into separate groups. Individuals were also divided into two groups based on the age of onset, detection and identification of hearing loss in their child. (Early-detection group had achieved these before their child was 1 year old. Late-detection group had achieved these after their child was 1 year old. The mean scores of the participants were compared between the two groups in each category, separately for each construct. Relationship between the responses to different constructs in the questionnaire and these different factors pertaining to the parents was also assessed using logistic regression.

Chapter 4

RESULTS

The study involved the development and administration of a questionnaire to understand the hearing help seeking behaviour (HSB) in parents of children with hearing loss. The results are presented below, in line with the objectives of the study.

4.1 Development of the Questionnaire

The first objective of the study was to develop a questionnaire to assess the HSB in parents of children with hearing loss. The questionnaire was developed based on the barriers, motivators and compliance factors for hearing help seeking derived from previous literature, and from certain factors suggested by experienced audiologists. Thirty-one factors were compiled in this manner, which were classified under the six constructs of Health Belief Model (HBM), as listed in Table 4.1. Table 4.1 also indicates the reference for the inclusion of each factor.

The questionnaire was developed based on these factors. The first part of the questionnaire collected demographic information about the participants as well as the child with hearing loss. The second part was divided into the question statements developed based on the factors, and additional questions that collected information regarding certain audiological and non-audiological factors. The statements included in the second part of the questionnaire are given in Table 4.2. The complete questionnaire in the format (Google form) that it was used for data collection is included in the Appendix.

Table 4.1: *The factors compiled under each construct of HBM along with the source of derivation*

Constructs of HBM	Factors	Source
Perceived Susceptibility	<ul style="list-style-type: none"> • Family history of hearing loss • Complication during pregnancy • Child on constant medication • Premature birth of the child • Poor response of child to sound 	<p>Kasper et al. (2017)</p> <p>Swanepoel & Almec, (2008)</p> <p>Harrison & Roush, (1996)</p> <p>Expert opinion</p>
Perceived Severity	<ul style="list-style-type: none"> • Child will not be able to speak • Child will be treated differently by society • The child will not be independent • Poor quality of education, life and future of the child • Social isolation of the child 	<p>Blamey et al. (2001)</p> <p>Expert opinion</p> <p>Expert opinion</p> <p>Expert opinion</p> <p>Expert opinion</p>
Perceived Barriers	<ul style="list-style-type: none"> • Doctor did not suspect hearing loss • Unaware of hearing loss in child • Poor access to hearing health service • Financial difficulties • Passing neonatal hearing screening • Poor support from home • Concern about society's reaction/Social stigma? 	<p>Schulz et al.(2016)</p> <p>Swierniak et al. (2021)</p> <p>Bush et al. (2014)</p> <p>Ravi & Gunjawate, (2020)</p> <p>Young and Tattersall (2007)</p> <p>Cameron et al. (1993)</p> <p>Expert opinion</p>
Perceived benefits	<ul style="list-style-type: none"> • Emergence of speech in the child • Attending normal school • Becoming independent • Good quality of life 	<p>Expert opinion</p> <p>Haddad et al.(2019)</p> <p>Expert opinion</p> <p>Expert opinion</p>

	<ul style="list-style-type: none"> • Acceptance by the society 	Expert opinion
Cue to action	<ul style="list-style-type: none"> • Doctor's referral • Poor auditory response to loud sounds • Got to know about hearing loss and its consequences through awareness camp • Motivated by family members and friends • Parents' sense of responsibility • The desire for good communication skills in the child 	<p>Slovik et al. (2020)</p> <p>Laplante-Lévesque et al.(2012)</p> <p>Expert opinion</p> <p>Fitzpatrick et al. (2008)</p> <p>Expert opinion</p> <p>Expert opinion</p>
Perceived Self-efficacy	<ul style="list-style-type: none"> • Recommendation by multiple specialists • Financial support • Child can take care of hearing aid herself/himself 	<p>Expert opinion</p> <p>Ravi & Gunjawate (2020)</p> <p>Expert opinion</p>

4.1.2 Validating the questionnaire

Content validity of the questionnaire was assessed by three professionals in rehabilitative audiology, with a minimum of three years of experience each. The suggestions made by them were considered to modify the questionnaire. The suggestions were with regard to defining age in weeks for premature birth, defining social isolation with example, and changing the key statement of construct 6 to improve comprehension. It was also recommended to change the statement- 'the doctor we would consult didn't suspect hearing loss' to 'the doctor we consulted didn't suspect hearing loss'. All the changes recommended were incorporated. Three lay persons who validated the questionnaire for its readability and clarity of meaning

were all able to comprehend the questions well, and no changes were recommended by them.

Table 4.2: *The statements included under the different domains of HBM*

Construct of HBM	Abbreviation	Statements
Perceived Susceptibility	<p>S1A</p> <p>S1B</p> <p>S1C</p> <p>S1D</p> <p>S1E</p> <p>S1F</p>	<p>We suspected hearing loss in our child because;</p> <p>there were other members in the family with childhood hearing loss.</p> <p>there were complications during pregnancy</p> <p>child was on constant medication for health alignment.</p> <p>the child had born pre-maturely.</p> <p>the child would respond to sounds poorly</p> <p>we felt that the child was responding to all sounds very well</p>
Perceived Severity	<p>S2A</p> <p>S2B</p> <p>S2C</p> <p>S2D</p> <p>S2E</p>	<p>We were worried that because of the hearing loss,</p> <p>our child will not be able to speak and communicate well</p> <p>our child will be treated differently by the society</p> <p>our child will have poor quality of life, education, and future.</p> <p>our child will be socially isolated.</p> <p>our child will never become independent.</p>
Perceived Barriers	<p>S3A</p> <p>S3B</p> <p>S3C</p> <p>S3D</p> <p>S3E</p>	<p>We did not get the child tested/treated for hearing loss because;</p> <p>the doctor we consulted didn't suspect hearing loss.</p> <p>we did not know that child will have hearing loss.</p> <p>of the poor access to hearing testing facility.</p> <p>we had financial difficulties.</p> <p>the child had passed hearing screening at birth.</p>

	S3F	we did not have support from home.
	S3G	we were worried about society's reaction.
Perceived Benefits		We expected that by treating for hearing loss,
	S4A	our child will be able to speak well.
	S4B	our child will go to normal school.
	S4C	our child will become independent.
	S4D	our child will have good quality of life.
	S4E	our child will be appreciated and accepted by society.
	S4F	our child will not have good quality of life.
Cue To Action		We got our child tested for hearing loss because;
	S5A	we were referred by doctor we consulted.
	S5B	we felt that the child was not responding even to very loud sounds.
	S5C	we got to know about hearing loss and its consequences from an awareness camp.
	S5E	we were motivated to go for testing by family members and friends.
	S5F	we wanted the child to speak and communicate well.
Perceived Self-efficacy		We were motivated to get our child tested/treated because,
	S6A	the child was old enough to take care of any hearing device by himself/herself.
	S6B	we had sufficient financial support.
	S6C	we consulted multiple specialists and everyone recommended hearing testing.

4.2 Reliability Analysis of the Developed Questionnaire

To assess the reliability of the questionnaire, Cronbach's alpha was calculated for each construct using participant's responses. The responses for the two catch questions were reverse scored before checking the reliability of responses. Cronbach's alpha values ranged from 0.628 to 0.649 for six different constructs of HBM (Table

4.3). The overall alpha coefficient value of the questionnaire was 0.646, suggesting moderate reliability.

Table 4.3: *Cronbach's alpha coefficient value obtained for each construct of HBM*

Constructs	Cronbach's alpha coefficient
Perceived Susceptibility	0.644
Perceived Severity	0.628
Perceived barriers	0.632
Perceived benefits	0.649
Cue to action	0.639
Perceived self-efficacy	0.643

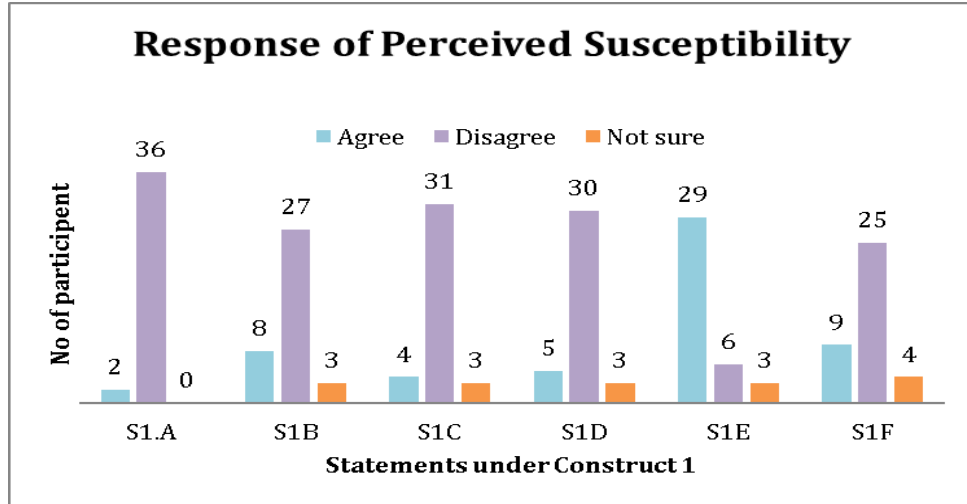
4.3 Outcome of the Survey

The responses obtained from 38 participants for the questionnaire on the 3-point scale for the 6 different constructs- perceived susceptibility, perceived severity, perceived barriers, perceived benefits, cue to action, and perceived self-efficacy are given in the graphs below.

4.3.1 Perceived susceptibility

Figure 4.1 shows the responses to the questions under the construct Perceived susceptibility. Results show that 76.3 % of the participants suspected hearing loss in their child because the child was responding poorly to sounds, 21% suspected because of complications during pregnancy, 13% suspected because of the child's premature birth, and 10.5% suspected because the child was on constant medication for his health. Only 5% of the participants perceived susceptibility for hearing loss in their children because of family history. For the negative scored question, after reverse scoring only 65% reported that the child is not responding to loud sounds.

Figure 4.1: Number of participants who responded 'Agree', 'Disagree', or 'Not sure', for the 6 statements under construct 1 – 'Perceived susceptibility'.



4.3.2 Perceived Severity

Figure 4.2 shows the responses obtained from the participants under the construct of Perceived Severity. It was seen that 84% individuals perceived severity of hearing loss by the child's inability to speak or communicate in future. 57.8% participants thought that the child will have poor quality of life, education, and future, 52.6% thought that due to hearing loss the child will be treated differently by the society, and 47.3% individuals were concerned that the child will be isolated or will not be independent.

4.3.3 Perceived barriers

Figure 4.3 shows the responses obtained from the participants under the construct of Perceived Barriers. It was seen that perceived barriers in 44.7% of the participants were financial difficulties, false negative neonatal hearing screening reports and that they did not think that their child has hearing loss. Poor access to hearing health care was perceived as a barrier by 23.6% of participants. 21% reported

that their doctor did not suspect hearing loss, and 10.5% were worried about society's reaction.

Figure 4.2: Number of participants who responded 'Agree', 'Disagree', or 'Not sure', for the 5 statements under construct 2 – 'Perceived Severity'.

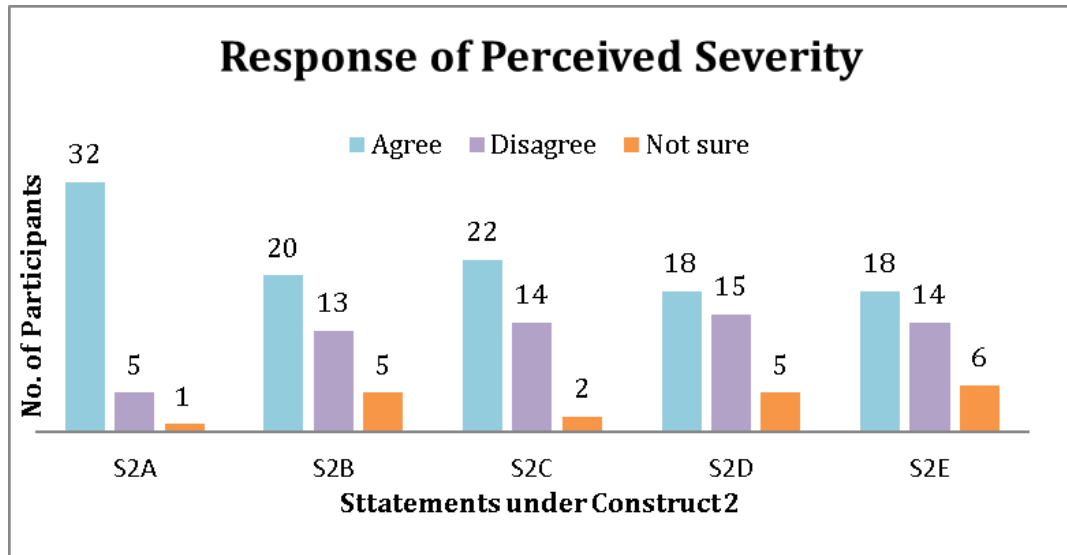
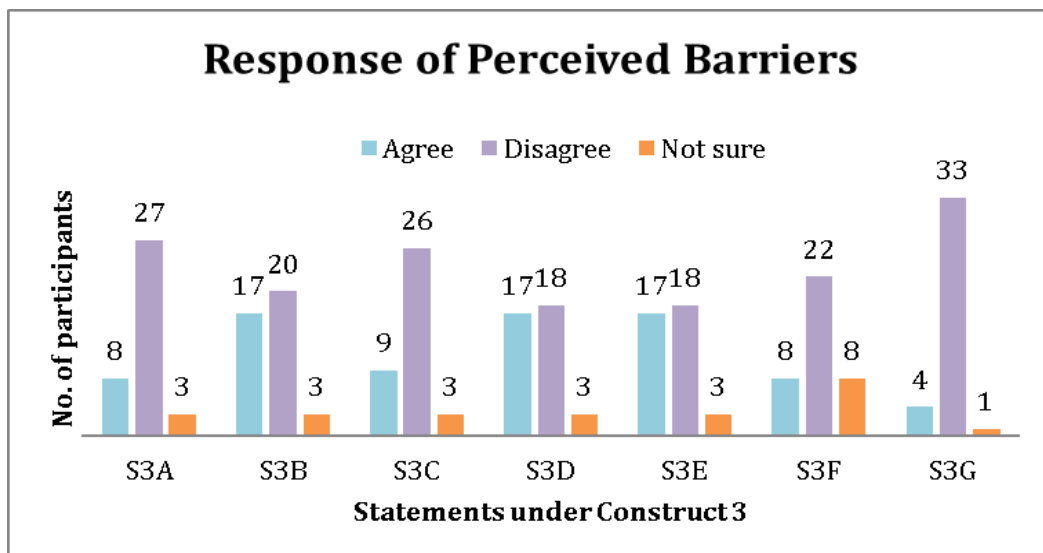


Figure 4.3: Number of participants who responded 'Agree', 'Disagree', or 'Not sure', for the 7 statements under constructs 3- 'Perceived Barriers'



4.3.4 Perceived Benefits

Figure 4.4 shows the responses obtained from the participants under the construct of Perceived Benefits. It was seen that around 95% of participants perceived

that their child will speak and become independent by treating hearing loss. 97.3% expected their child to go to normal school after treatment. 92% thought that treating hearing loss in their child can lead to acceptance by the society and 84% of participants expected good quality of life. For the negative scored question, after reverse scoring 78.9% reported that their child will have good quality of life as a result of treatment.

4.3.5 Cues to action

Figure 4.5 shows the responses obtained from the participants under the construct of Cue to Action. It was seen that cue to action for 97.3% of participants was the desire for the child should speak and communicate well. 94.7% thought it was their responsibility to get the child tested and treated, and 84% felt that they were prompted because their child was not responding to very loud sound. A doctor referred for hearing testing in 63% of participants while 55% were prompted to act by their family members and friends.

Figure 4.4: *Number of participants who responded 'Agree', 'Disagree', or 'Not sure', for the 6 statements under constructs 4- 'Perceived Benefits'*

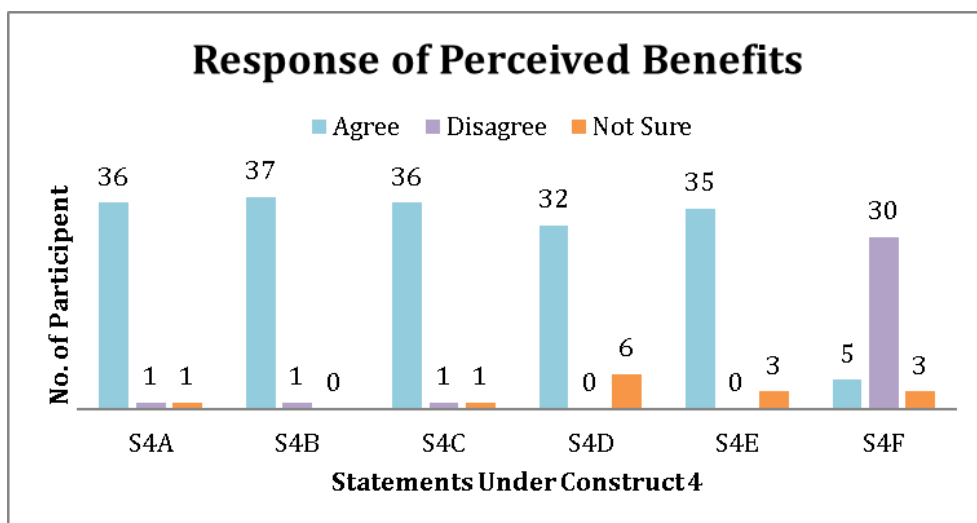
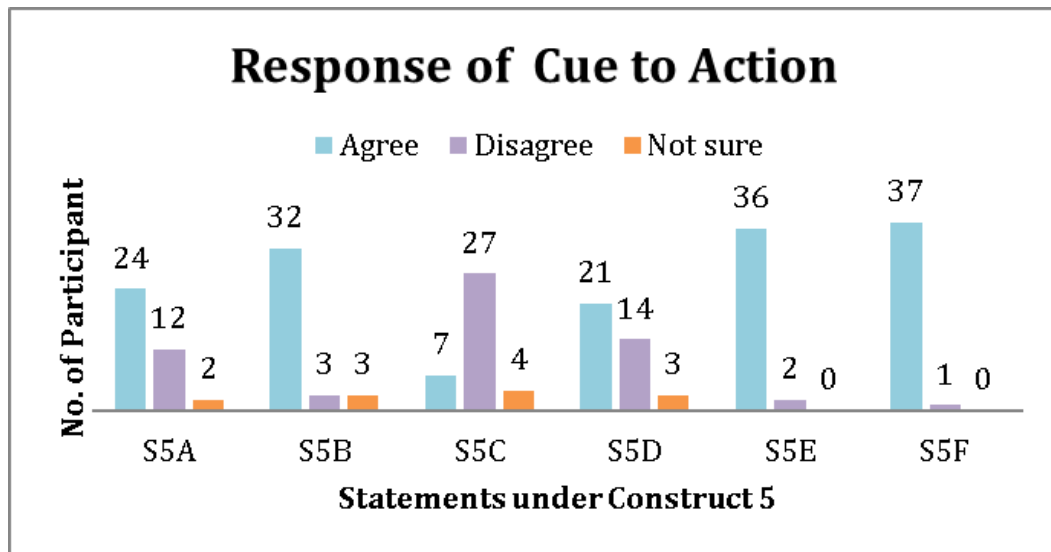


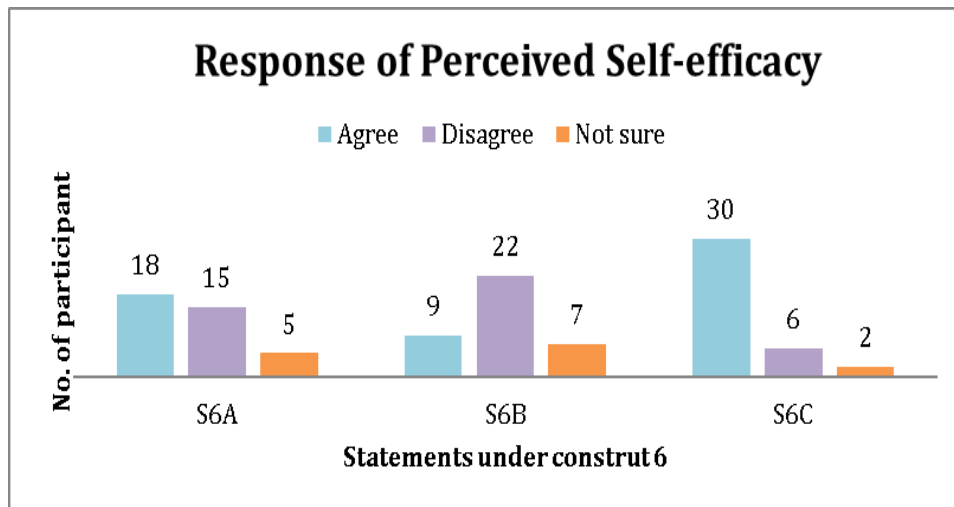
Figure 4.5: Number of participants who responded 'Agree', 'Disagree', or 'Not sure', for the 6 statements under constructs 5- 'Cues to action'



4.3.6 Perceived Self-efficacy

Figure 4.6 shows the responses obtained from the participants under the construct Perceived self-efficacy. It was seen that 78.9% of the participants perceived their self-efficacy for testing/ treating their child after they consulted multiple specialist and everyone recommended hearing testing for the child, 47% went for hearing testing of because they thought their child can take care of his/her hearing aid by himself/herself, and only 23.6% went for hearing testing because of their financial stability.

Figure 4.6: *Number of participants who responded 'Agree', 'Disagree', or 'Not sure', for the 3 statements under constructs 6- 'Perceived self-efficacy'*



4.6 Relationship of Audiological and Non-audiological Factors with the Scores obtained in Different Constructs of the Help Seeking Behaviour Questionnaire

The mean of the scores obtained in the six constructs of HBM by the participants who responded yes/no for each of the questions assessing audiological or non-audiological factors are given in Figures 4.7 to 4.12.

- 1) The mean scores of perceived severity and barriers were higher for those who responded 'yes' for availability of hearing health care service than those who responded 'no'.
- 2) The mean scores of the constructs perceived susceptibility, perceived severity, perceived barriers, perceived benefits and perceived self-efficacy were higher for those who were aware about hearing loss and its consequences before their child was born than those who were not aware.
- 3) The mean score of the constructs perceived susceptibility, perceived barriers and perceived severity were higher for those whose child underwent hearing screening at birth than those who did not undergo hearing screening.

- 4) The mean score of construct perceived susceptibility, perceived severity, perceived benefits and perceived self-efficacy were higher for those whose child's hearing loss onset was below 1 year of age than those whose onset was above 1 year of age as reported.
- 5) The mean scores of constructs perceived severity and perceived barrier was higher than whose hearing loss detected below 1 year of age than who are detected above 1 year of age.
- 6) The mean score of construct cue to action was lower for those whose child's hearing loss was identified below 1 year of age than those identified above 1 year of age.

Figure 4.7: Mean of the scores of participants who responded 'yes' or 'no' to the 'availability of hearing healthcare services', under the different constructs of HBM.

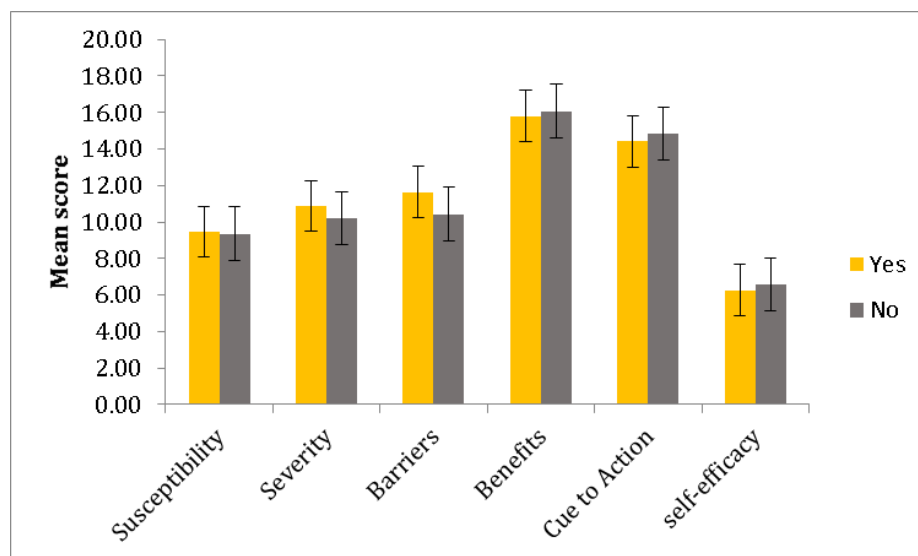


Figure 4.8: Mean scores of individuals who responded 'yes' or 'no' to the 'awareness of hearing loss and its consequences, under the different constructs of HBM

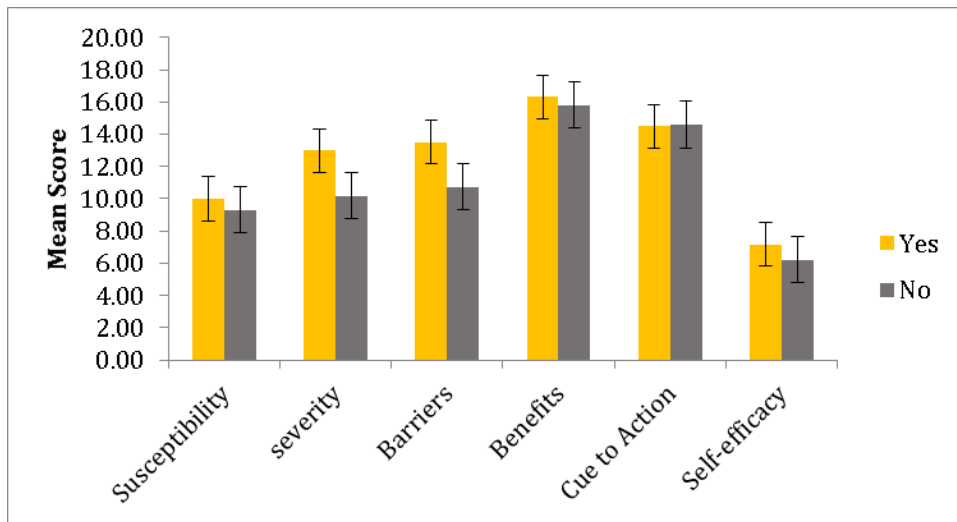


Figure 4.9: Mean scores of individuals who responded 'yes' or 'no' to the 'hearing screening done at birth', under the different constructs of HBM

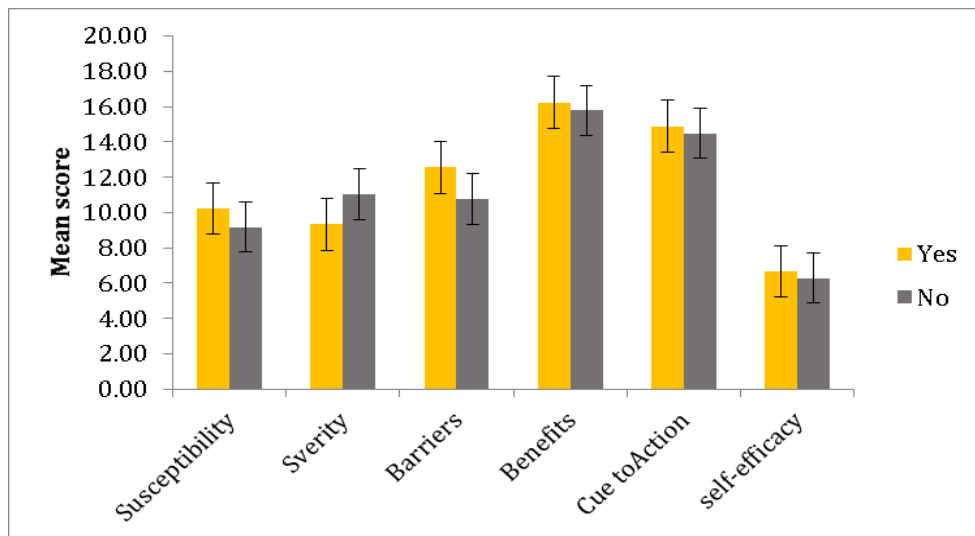


Figure 4.10: Mean scores of individuals who responded 'below 1 year' or 'above 1 year' to the 'onset of hearing loss in children, under the different constructs of HBM

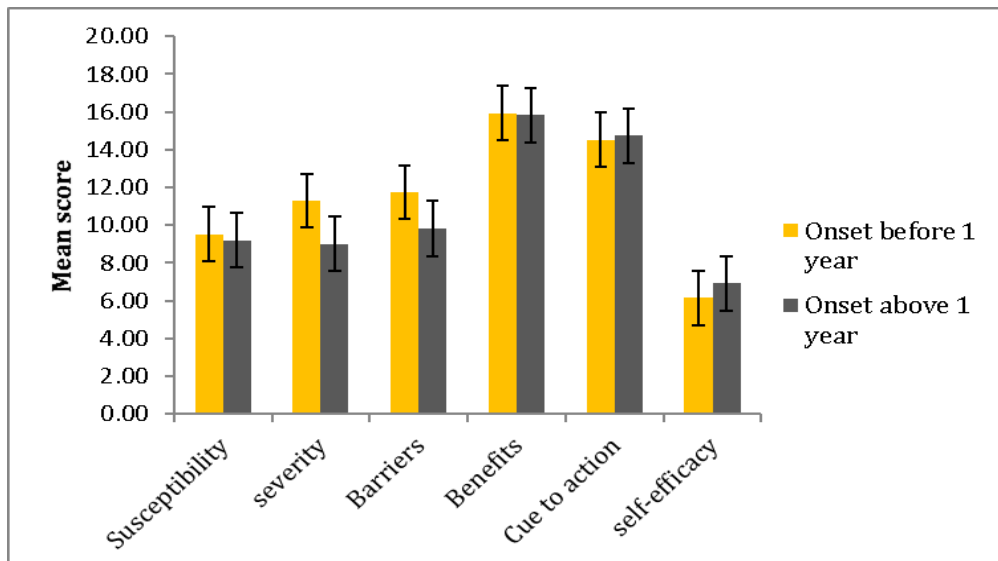


Figure 4.11: Mean scores of individuals who responded 'below 1 year' or 'above 1 year' to the 'detection of hearing loss in children, under the different constructs of HBM

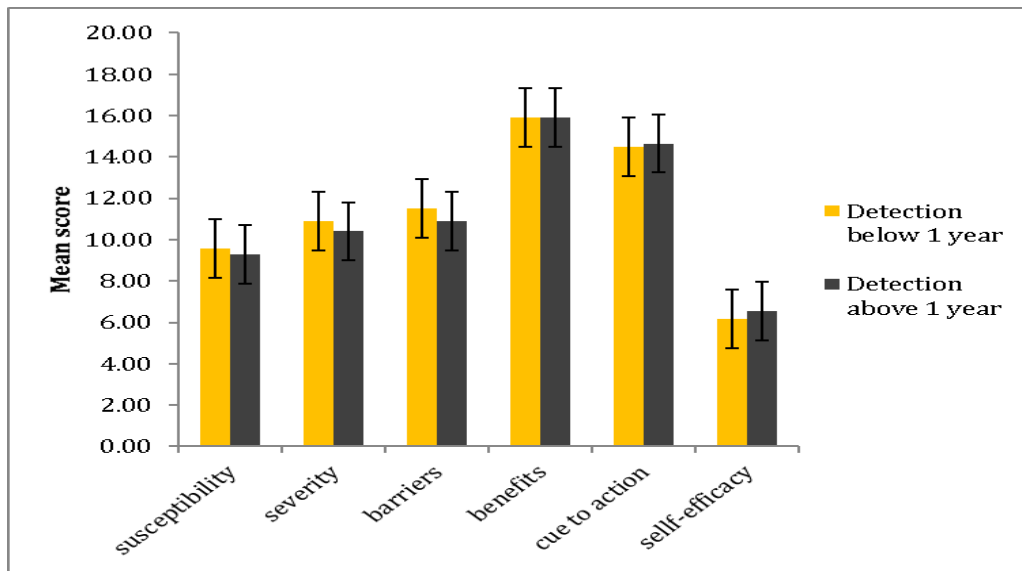
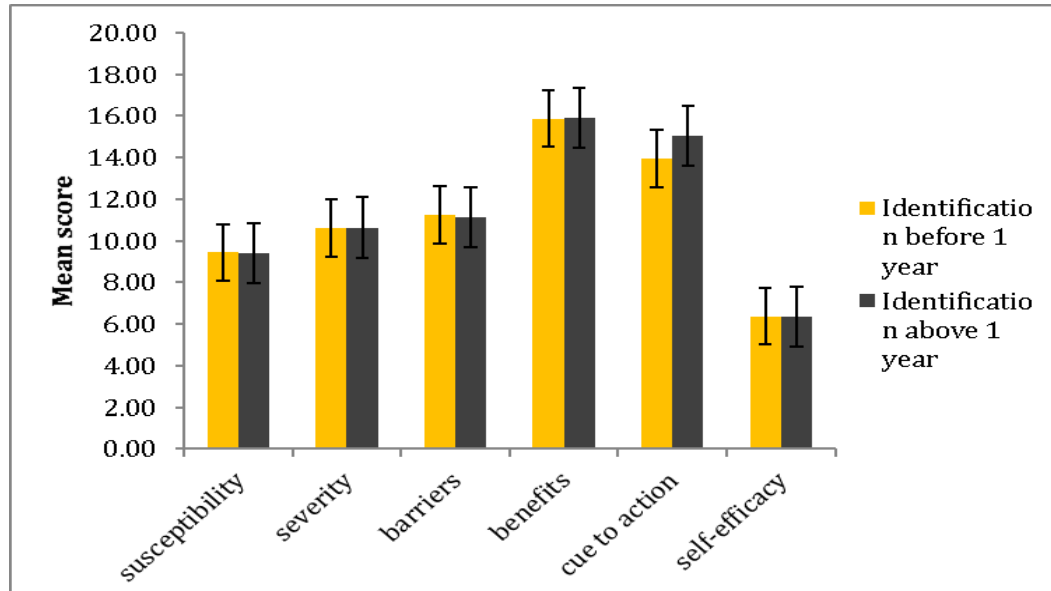


Figure 4.12: Mean scores of individuals who responded 'below 1 year' or 'above 1 year' to the 'identification of hearing loss in children, under the different constructs of HBM



4.5. Logistic Regression

An attempt was made to generate a model of hearing health behaviour (awareness of hearing loss and its consequences, availability of hearing health care services and hearing screening at birth) from the response scores obtained from the questionnaire. The results of the logistic regression analysis are given in Tables 4.5 to 4.7. No association was observed between the factors studied, and the responses obtained under the different constructs of the questionnaire.

Table 4.5: *Results of binary logistic regression analysis to predict hearing health behaviour (availability of hearing health service at their place) from Help Seeking Behaviour Questionnaire*

Predictor	B	Wald	p-value	Odd ratio
Susceptibility	0.154	0.471	0.492	1.167
Severity	-0.093	0.800	0.371	0.912
Barriers	-0.292	3.178	0.075	0.746
Benefits	0.499	1.091	0.296	1.647
Cue to action	0.248	1.304	0.253	1.282
Self-efficacy	0.118	0.201	0.654	1.126

Table 4.13: *Results of binary logistic regression analysis to predict hearing health behaviour (awareness about hearing loss and its consequences before child's birth) from Help Seeking Behaviour Questionnaire*

Predictor	B	Wald	p-value	Odd ratio
Susceptibility	0.272	0.494	0.482	1.313
Severity	-0.490	3.420	0.064	0.613
Barriers	-0.352	2.694	0.101	0.704
Benefits	-0.296	0.479	0.489	0.744
Cue to action	0.583	1.929	0.165	1.791
Self-efficacy	-0.769	2.007	0.157	0.464

Table 4.14: *Results of binary logistic regression analysis to predict hearing health behaviour (hearing screening at birth) from Help Seeking Behaviour Questionnaire*

Predictor	B	Wald	p-value	Odd ratio
Susceptibility	-0.194	0.668	0.414	0.824
Severity	0.141	1.497	0.221	1.151
Barriers	-0.055	0.104	0.747	0.946
Benefits	-0.229	0.200	0.655	0.795
Cue to action	-0.143	0.368	0.544	0.866
Self-efficacy	0.093	0.092	0.762	1.097

Chapter 5

DISCUSSION

The uptake of hearing healthcare services in the pediatric population in India is poor compared to the developed countries with established early hearing detection and intervention (EHDI) programs. Understanding the factors that influence the hearing help seeking behavior (HSB) of parents of children with hearing loss in the country may help us understand the reasons for the same. It may also help us to take important steps to improve their uptake of hearing health care services.

With this view, the preliminary aim of this study was to develop a questionnaire based on the constructs of Health Belief Model (HBM) that assesses the hearing HSB of parents of children with hearing loss. The study also aimed to administer this questionnaire on parents of children with hearing loss, and to assess the reliability of the questionnaire based on their responses. The details of the developed questionnaire and the outcomes of the questionnaire administration are discussed under the following headings

1. Questionnaire to assess hearing help seeking behavior
2. Reliability of the questionnaire
3. HSB derived from the questionnaire

5.1. Questionnaire to Assess Hearing Help Seeking Behaviour

The questionnaire was developed based on factors related to HSB reported in the literature and the factors recommended by experienced audiologists. Accordingly, the developed questionnaire contained 33 statements arranged under the six different constructs of HBM, namely perceived susceptibility, perceived severity, perceived barriers, perceived benefits, cue to action and perceived self-efficacy. Most of the factors reported in literature could be directly classified under

the constructs of perceived susceptibility, cues to action, or perceived barriers. This was because most of the studies have explored the motivators, barriers and compliance factors related to hearing HSB (Abdellaoui & Tran Ba Huy, 2013; Bille & Parving, 2003; Cox et al., 2005; Duijvestijn et al., 2003; Hickson et al., 2014; Kochkin, 2007; Laplante-Lévesque et al., 2010). The present study, however, tried to develop a questionnaire to understand other belief constructs and external factors (explained by the HBM) that may have influenced the parents' HSB. The factors under these constructs were mostly derived from the suggestions from the experts.

5.2 Reliability of the Questionnaire

Reliability analysis of the questionnaire was carried out using Cronbach's alpha. The scores ranged from 0.628 to 0.649 for the 33 statements of the questionnaire. Cronbach's alpha for a given questionnaire with a value 0.7 to 0.5 indicates moderate internal consistency, and the Cronbach's alpha value should be at least 0.70 to show that a questionnaire has adequate internal consistency (Aithal & Aithal, 2020). However, Kline (1999) states that for questionnaires dealing with psychological constructs, because of the diversity of the constructs being measured, scores below 0.7 are acceptable. Also, even though the reliability of these construct is not high, it is on par with the values observed for other assessment tools based on HBM (Champion & Scott, 1997; Pinto et al., 2006).

5.3 HSB derived from the Questionnaire

Outcomes of the survey reflected the experiences of the participants as parents of children with hearing loss. In most cases, parents noticed hearing loss in their child before other family members, friends, or doctors. Absence of response to sounds was their major reason to notice hearing difficulty in their child. This

outcome is similar to other reports in the literature (Olusanya et al., 2005; Swierniak et al., 2021). However, it should be noted that there was minimal mention of other factors like family history of hearing loss, complications during pregnancy, child on constant medication, or premature birth of the child from the participants. The influence of these factors may have been under-represented in the responses obtained in the survey. It may also be because of poor awareness regarding such risk factors of hearing loss (Ravi et al., 2016). It may be more prudent to make a definite comment about the frequency of occurrence of these factors under ‘perceived susceptibility’ after obtaining responses to the questionnaire from a more representative population.

Under the construct of ‘perceived severity’, most parents were concerned about the poor development of speech communication in their child due to hearing loss. This indicates that they were mostly aware of the immediate impact of hearing loss. They were also concerned about the impact of hearing loss on the child’s future and education. The reaction of the society and the child’s ability to be independent were also of concern. These responses suggest that parents were aware and concerned about the impact of hearing loss on the child’s life. Similar to the reports in adult population, the findings of the study indicate that more the perceived severity, better is the awareness of hearing loss and its consequences (Crandell et al., 2004; Svensson et al., 2004).

Nearly half of the participants reported that the major barrier to detect hearing loss in their child was not expecting their child to have hearing loss. Consequently, they did not suspect hearing loss in the child. Lack of awareness regarding hearing loss and normal auditory behavior, reported in previous literature (Swierniak et al., 2021) is reflected in this observation. Similar to reports in previous

literature on hearing HSB on parents of children with hearing loss (Merugumala et al., 2017; Ravi & Gunjawate, 2020), financial difficulties also delayed the diagnosis of hearing loss. Even though most of the participants in the present study did not have financial support, they decided to get the hearing loss treated. This indicates that their concern about the child's future outweighs their financial concerns.

The findings revealed that some of the children had passed neonatal hearing screening. This gave the parents a false sense of assurance. The reason for this could be a false negative screening report or late onset paediatric hearing loss. Risk factors like cytomegalovirus infection, genetic syndromes associated with progressive hearing loss, neurodegenerative disorders, trauma, or bacterial meningitis may cause late onset hearing loss. Auditory neuropathy spectrum disorders (ANSD) may also be undetected at the first level of screening. Since these are recognized high risk factors, the finding hints at the need for efficient re-screening strategy for infants with these risks, regardless of the outcomes of the initial screening. One possible strategy is to include automated ABR while screening infant with high risk factors. Otoacoustic emission along with automated ABR is known to reduce false negative by less than 5%. The finding also indicates poor awareness among the parents about these causes and the need to monitor the auditory behaviour of their child. Therefore, efficient and compulsory parental counselling after first stage of screening regarding auditory development and language development is warranted (Wroblewska-Seniuk et al., 2017).

Before the initial hearing assessment of their child, parents considered the immediate as well as long-term outcomes of the necessary treatment. Most of the parents agreed that the benefits provided by treatment of hearing loss would be good speech development in the child, opportunity to attend normal school, self-efficacy

and good quality of life.

Cues to action for most of the participants were their sense of responsibility to treat their child's hearing loss; they wanted their child to speak and communicate well. Parents were ready to take responsibility of their child's development. This may be expected to positively influence the child's development. Most of the participants were referred by their general physicians for audiological evaluation. This indicates good awareness about hearing loss and assessment in general physicians. Again, concern about the child's poor responses to sounds influenced the parents' help seeking decisions. This indicates that parents suspicion of hearing loss in their child will lead to earlier diagnosis of hearing loss, if any.

The findings of the study indicate that parents take their decision of treating hearing loss based on the recommendations of different specialists. The information provided by health professionals is reported to influence the parental decision-making process, with printed health information playing a particularly essential role in this process (Decker et al., 2012). Good awareness about hearing loss and its management can be created at a health professional's office itself. This may be implemented as a compulsory awareness program involving counselling for every parent and as good referrals to an Audiologist when hearing loss is suspected in a child. An inter-disciplinary approach where an audiologist's consultation is sought as part of new-born's routine health assessment will be extremely helpful in increasing the reach to hearing healthcare for every infant.

Less than half of the participants reported that they decided to procure hearing aids once they were convinced that their child can take care of his/her hearing aid by himself/herself, indicating that self-efficacy too is an important aspect considered by parents. Similar reports exist in studies from adult population. Meyer

et al. (2014) showed that an individual's ability to handle hearing aid will lead to uptake of hearing aid in elderly people. Cost of hearing aids may be a reason for the parents to be concerned about procuring hearing aids before the child can independently take care of the device.

It was also observed in the study that the mean scores of Perceived severity and Perceived barriers were higher for the participants who had availability of hearing health care service in their area. This means that the barrier of 'poor access to hearing health care facility' may not have influenced these individuals. Even with good access to hearing health care facility, their perceptions of barriers were high; indicating that good access to a hearing health care facility alone will not help a parent seek help for their child's hearing loss. Other factors also will have to be addressed to reduce their perceived barriers. As has been stated before, a lack of awareness about hearing loss in itself was a major barrier perceived by the participants. If parents are more aware of hearing loss, availability of hearing health service may be expected to play an important role in improving the hearing HSB of the parents.

The mean score of constructs susceptibility, severity, barriers, benefits, cues to action, and self-efficacy were higher for those who were aware about hearing loss and its consequences before their child was born than those who were not aware. Perception of higher susceptibility, severity, benefits, and cues to action may indicate their knowledge about the consequences of hearing loss. The score of construct 'barrier' can be higher because of barriers such as failure to recognise deafness, the dominant role of elders in household decisions, belief that deafness would resolve, reassurance from a child's overall good health, lack of funds, and transportation barriers to reach the centre, particularly from rural areas, which are known to play an

important role in rehabilitation of children with hearing loss (Merugumala et al., 2017).

The mean score of the constructs perceived susceptibility, perceived barriers and perceived severity were higher for those whose child underwent hearing screening at birth than those who did not undergo hearing screening. Jatto et al. (2018) reported that acceptance of neonatal hearing screening was linked to socioeconomic status and educational level. However, the participants of the present study were largely unaware of the factors that cause hearing loss in children, and the mothers had insufficient understanding about newborn hearing screening and the risk factors for infant hearing loss, despite their willingness to take the newborn hearing test. But, it is possible that an initial neonatal hearing screening assessment may have sensitized them to the possibility of hearing loss in children and in turn, their perception of severity and susceptibility of hearing loss in the child.

The mean scores of the constructs perceived susceptibility, perceived severity, perceived benefits, and perceived self-efficacy were higher for those who detected hearing loss in their child before 1 year of age (early), compared to those who detected hearing loss after 1 year of age (late). The mean score of construct 'cues to action' was lower for the participants whose children were identified early compared to the participants whose children were identified late. This reflects the possible association of greater perception of susceptibility, severity, benefits, and efficacy with early approach for hearing health care. This finding furthers the importance of good awareness programs among parents of children with hearing loss. It is well established that early identification of hearing loss and appropriate intervention before the age of 6 months can increase the possibility of normal speech and language development in children with hearing loss (Shojaei et al., 2016). This

time interval is an important predictor of intervention outcomes and research has demonstrated that early identification can only be effective if early intervention is available as early as possible, at least within the first year of the child's life (JCIH, 2007).

Duncan (2009) states that it is important that the decision- making process is not rushed and that parents should be aware that they can take the necessary time to make an informed decision. If such informed decision needs to be taken by parents without delaying the precious time for language learning in their child, it is necessary that they are aware of hearing loss before, or as soon as their child is born. Community-based programs to create awareness about hearing loss, its consequences, and intervention options and universal hearing screening programs will be able to achieve that. François et al. (2015) reported that, if hearing loss is identified early and treated early, children with moderate, severe or profound hearing impairment can enter mainstream primary education in 85.4% of the cases.

The logistic regression results showed no association between the audiological and non-audiological factors studied, and the responses obtained under the different constructs of the questionnaire. This observation could be because the responses compared were from a small sample size (38 participants), or because of the limited points on the response scale (3 points). Logistic regression is mostly carried out on responses from scales with more number of response points. Also the groups divided into two groups based on different criteria did not have same number of participants. So, the participant groups may not have been well representative of the complete HSB since they were from a limited number, collected via convenience sampling.

Chapter 6

SUMMARY AND CONCLUSIONS

The *help seeking behaviour* (HSB) for hearing loss is influenced by many factors such as barriers, motivators and compliance factors. Studying these factors will help us to better understand the HSB in individuals with hearing loss, or in parents of children with hearing loss. Studies have examined the HSB of parents of children with hearing loss in terms of their approach to rehabilitation choices. However, no study has examined the HSB in such parents within the framework of a theoretical model of help seeking. This study aimed to understand HSB in parents of children with hearing loss based on the *Health Belief Model* (HBM).

A questionnaire was developed based on factors related to hearing HSB reported in the literature and the factors recommended by experienced audiologists. The developed questionnaire contained 33 statements arranged under the six different constructs of HBM, namely perceived susceptibility, perceived severity, perceived barriers, perceived benefits, cue to action and perceived self-efficacy. The questionnaire was validated by three audiologists and three lay people. The validated questionnaire was administered online using Google forms on thirty-eight parents of children with hearing loss via survey method. The reliability of the questionnaire was assessed using Cronbach's alpha. The overall Cronbach's alpha coefficient was 0.646, suggesting moderate reliability.

The important outcomes of the survey showed a lack of awareness regarding auditory behaviour, hearing loss and hearing health care among the participants. Once they suspected hearing loss in their child, most of the parents were concerned about the poor development of speech communication in their child. However, they reported major barrier in detecting hearing loss due to lack of awareness. Financial difficulties

and false negative screening reports were also important barriers. Most of the parents agreed that the benefits provided by treatment of hearing loss would lead to good speech development in the child, leading to a good quality of life. Cue to action for most of the participants was their sense of responsibility. Parents made assessment and rehabilitative decisions based on the recommendations of multiple specialists.

These findings indicate the need for a good public awareness program about hearing development, assessment, and treatment programs. A universal newborn hearing screening program with a protocol to assess late-onset hearing loss is also warranted. Appropriate referrals from medical doctors can improve the parents HSB. The study also showed that the parents were ready to take responsibility of their child's development, and this may be expected to positively influence the child's future.

Based on the findings of the study, it can be concluded that improving parental awareness about hearing loss and its consequences will improve the HSB in them. A compulsory awareness program involving counselling for every parent-to-be, universal newborn hearing screening program, appropriate and timely referral to an Audiologist when hearing loss is suspected in their child may all positively influence their HSB.

Limitations of study

1. The survey was carried out on a small sample size. So, the participant groups may not have been well representative of the study population. Also, the difference in the number of individuals in each group used for the group comparisons in the study may have resulted in poor results.
2. Correlation and regression measures could not be used for data analysis because of the limited 3 point rating scale used.

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APPENDIX I