

**PARENTAL STRESS IN PARENTS OF HEARING IMPAIRED CHILDREN:
AN EXPLORATORY STUDY USING ICF CLASSIFICATION**

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AUGUST 2022

CERTIFICATE

This is to certify that this dissertation entitled “**Parental Stress in caregivers/parents of Hearing Impaired Children: an exploratory study using ICF classification**” is the bonafide work submitted in part fulfilment for the degree of Master of Science (Audiology) of the student with Registration Number: **20AUD015**. 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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This is to certify that this Master's dissertation entitled "**Parental stress in parents of hearing impaired children: an exploratory study using ICF classification**" is the result of my own study under the guidance of Dr Nisha K V., (Guide) and Dr Prashanth Prabhu P., (Co-Guide) Department of Audiology, All India Institute of Speech and Hearing, Mysuru, and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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Dedicated to My Guide, Family,
individuals with hearing
impairment and their parents

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ABSTRACT

Parents of children with hearing impairment (HI) often face a lot of psychosocial issues apart from the economical and day-to-day adjustments concerning their disabled child. Therefore, addressing the stress in caregivers/parents of HI children from a biopsychological perspective may be more pertinent than from solely a biomedical model. The main aim of the study was to understand the problems and life effects in parents of HI children using the International Classification of Functioning, Disability and Health (ICF) framework and to correlate it with the responses from a close-ended questionnaire (item Caregiver Strain Questionnaire, CGSQ).

Using a prospective survey design, 100 parents of HI children participated in the study. Two ICF open-ended questions and a 21-item CGSQ were administered. The first question of ICF probed into problems or challenges that are faced by parents of HI children (problem question: PQ) and the second to their life effects (life effect question: LEQ). Responses were coded by three trained professionals and were linked to codes in ICF categories: body functions, activity limitation, environmental factors and personality factors.

A total of 862 codes were obtained. Bland-Altman analysis revealed high inter-coder reliability. 437 responses were related to problems faced and 425 responses were related life effects. Thirteen responses did not fit into any of the ICF categories. The descriptive (mean and median) analyses of the frequency count for overall responses revealed that participants had experienced more difficulties in PQ than LEQ, although they were not reaching statistical significance. Most of the responses were related to activity limitations, and participation restrictions (358/862), followed by body function (321/862), highlighting the stress induced limitations in their day-to-day activities from

a psychosocial perspective. In CGSQ, the item rated “Very much a problem” by most of the parents (56/100) was the sadness felt as a result of their child’s hearing problem. The second most reported stress parents faced were related to the future of their child. The least reported item was for the child getting into trouble with the neighbours, the school, the community, or law enforcement. There was no significant correlation between ICF domains and CGSQ responses. The responses coded to ICF show that parents of HI children encounter challenges in many domains, which are otherwise not assessed using questionnaires and hence are largely ignored in the conventional rehabilitation process.

Keywords. Stress, ICF framework, ICF codes, CGSQ, children with hearing impairment, parents

Chapter I

INTRODUCTION

Hearing loss (HL) is one of the most frequent congenital diseases in children. Reports show a world-wide prevalence of HL to be 1–3:1000 in healthy neonates, with majority of cases in the neonatal intensive care unit (Erenberg et al., 1999; Morton & Nance, 2009). Hearing loss prevalence in neonates in the Indian context is reported to be 1.59 to 8.8: 1000 newborns (Verma et al., 2022). The prevalence of HL in children ranged from 6.6 to 16.47 %, frequent cause of hearing loss was otitis media (Verma et al., 2022).

Children with HL are a heterogeneous population in terms of their type of HL loss, laterality (bi- or unilateral), severity, nonverbal cognitive performance, and other problems that can impact up to 40% of them (Annual Survey of Deaf and Hard of Hearing Children and Youth, 2009; Braun et al., 2015). HL in children invariably causes speech and language development delays, affecting communication and academic success (Lieu et al., 2020).

When the child is diagnosed with hearing impairment (HI), it will be more stressful for the parents and other family members (Lederberg & Golbach, 2002; Quittner et al., 2010). Handling children with HI may be challenging for parents (Prakash, et al., 2013) as it is difficult for them to keep their child's routines consistent, negatively impacting the parent-child relationship (Figner et al., 2009). They are more likely to experience feelings of helplessness, grief, anger and guilt and a sense of isolation within the parent-child dynamic which is inevitable and can affect the parent-child connection and language learning performance (Mellon, 2009).

According to Neece et al. (2012), the stress related to parents affects both parent and child. Most of the studies on the stress of parents of children with disabilities primarily focus on the mother's stress levels than the father, as mother-child interactions are a cornerstone in language development (Boyd, 2002; Hassall et al., 2005; Lederberg & Golbach, 2002b; Miranda et al., 2019; Pipp-Siegel, 2002). They usually spend more time with their mothers than their fathers. A host of studies have confirmed that mothers' behaviours are linked to concurrent and later child outcomes in language, cognition, and social behaviour (Cassidy, 1988; Cummings & Davies, 1994; Pancsofar & Vernon-Feagans, 2006). Such studies show that mothers of children with disabilities had higher stress than their fathers (Lederberg & Golbach, 2002; Sharpley et al., 2009). In contrast, some studies show both parents experience equivalent stress (Gray, 2006; Taber, 2010). A survey of both parents of a HI child found that both parents have equal stress (Zaidman-Zait et al., 2016). Kasin et al. (2020) found that parents' psychological distress and functional impairment may be influenced by psychological inflexibility, low income, other disabilities tangent to hearing loss, and younger child age. They evaluated 296 parents of children with HI, approximately 15 to 34% reported various psychosocial issues, including psychological distress, overall well-being, and functional impairment.

Parents experiencing negative emotions are less effective at nurturing language, facilitating psychosocial development, and promoting intervention strategies for their children with HI, impacting their child's developmental outcomes (Hadadian & Rose, 1991; Meizen-Derr et al., 2008). Parenting stress has repeatedly been related to increased internalising and externalising behaviour problems in their children. Additionally, parents' negative and coercive interactions with their children and authoritarian and power-assertive discipline strategies (Jennings, 2007) further increase

behavioural problems in children with HI. Parental stress also influences a newborn's sense of security, particularly when the parent suffers from emotional issues (Neece et al., 2012). Hence, the overall impact of parental stress cannot be directly inferred from the biomedical model as they lack considering societal attitudes towards these individuals, such as social isolation, prejudice, and discrimination (Smart, 2006). In contrast, the biopsychological perspective may be more pertinent to comprehensively documenting stress's social and psychological impact on parents of children with HI.

There is enough evidence to believe the psychosocial impact among parents of children with HI. The available questionnaires intended to address stress-related aspects in parents do not cover all mental, emotional and financial issues. Although close-ended questionnaires can highlight a few psychosocial and attitude-based issues faced by parents, most of them are not validated across diverse cultural and ethnic groups. In contrast, widespread ramifications of parental stress levels can be disentangled and coded under different categories of the International classification of functioning, disability and health (ICF) framework. Researchers suggest that using open-ended questionnaires to elicit the responses will provide broader responses (Stephens & Pyykkö, 2011), which can then be coded using ICF. The overall parental stress can be assessed with the help of the ICF theoretical framework given by the World Health Organization (2001). Although most are not used clinically, the ICF has more than 1500 categories. ICF integrates the social model (wherein disability is viewed as a consequence of societal conditions) and the medical model (for which disability is considered connected to a person's bodily dimension, caused by a disease) into a bio-psycho-social approach.

The ICF uses numerical category codes with broad applicability in clinical settings or research (Meyer et al., 2016). The classification is based on a hierarchical structure consisting of A) Functioning & Disability and (B) Contextual factors. The Functioning & Disability is further divided into (A1) Body structures (anatomical parts of the body) and Body functions (physiological functions of body systems), (A2) Activities (execution of a task or an action by an individual) and Participation (involvement in a life situation). Likewise, the Contextual factors are further divided into (B1) Environmental factors (the physical, social, and attitudinal environment) and (B2) Personal factors (the particular background of an individual's life and living) (WHO, 2001). Each component comprises various domains; within each domain, categories are the classification units. An individual's health and health-related conditions can be documented by selecting the appropriate category code(s) (numeric codes), which specify the extent or the magnitude of the functioning or disability in that category or the extent to which an environmental factor is a facilitator or barrier (WHO, 2001).

Furthermore, the WHO initiated the ICF core sets projects to facilitate ICF's applicability in clinical settings and research. A core set is a set of ICF categories of particular relevance for a specific diagnosis or health condition. The ICF core sets for hearing loss cover both auditory and non-auditory domains (Granberg et al., 2014). According to the ICF, the sense of hearing is considered a part of the body function (coded as b230). Using ICF core sets for parental stress can establish a comprehensive understanding of the parental stress due to their child's HL. Currently, no studies incorporate the ICF framework for addressing the parental stress of parents of children with HL.

1.1. Need for the study

There is enough evidence to believe the psychosocial impact among parents of children with HI, addressing stress or health-related factors in this population through ICF classification may lead to broader recognition, awareness, identification and appropriate support. Further early identification of the stress factors will help provide proper guidelines, and devise appropriate management strategies and family-based intervention, which can positively impact children's progress.

The available questionnaires address not all mental, emotional and financial issues. Although questionnaires that are close-ended highlight a few psychosocial and attitude-based issues faced by parents, most of them are not validated across diverse cultural and ethnic groups. Using ICF to code open-ended parental responses can give a broader understanding of their issues more close-ended questionnaires.

1.2 Aim of the study

The study aimed to determine the impact of stress on parents of HI children using a multidimensional approach (ICF framework) and a closed-ended questionnaire based approach (Caregiver Strain Questionnaire: CGSQ, Brannan et al., 2016). The responses derived using two open-ended questions (problem and life effects) were coded onto ICF categories. In addition, the study also tried to correlate the ICF - category based deficits to the scores obtained on the parental stress questionnaire.

1.3 Objectives of the study

- To document the frequency of the problems and life effects faced by the parents/caregivers of children with HI using ICF classification specifically for the domains: (a) body function and body structures, (b) activities and

participation, (c) contextual factors, and environmental factors, and (d) personal factors.

- To evaluate the scores on the caregiver stress levels using CGSQ.
- To correlate the frequency of stress codes obtained for ICF with the response obtained for CGSQ.

Chapter II

REVIEW OF LITERATURE

One of the most prevalent sensory impairments in humans today is hearing loss (HL). Globally, around 34 million children under the age of 15 suffer from disabling hearing loss (HL)(WHO, 2001). However, most children with HL reside in low- and middle-income nations, with prevalence rates in South Asia, Asia-Pacific, and Sub-Saharan Africa being almost four times higher (WHO, 2001). Hearing loss prevalence in newborns in the Indian context varies from 1.59 to 8.8 per 1000 newborns (Verma et al., 2022). The prevalence of HL in children ranged from 6.6 to 16.47 %, frequent cause of hearing loss was otitis media (Verma et al., 2022).

Due to advanced technology and the successful implementation of universal newborn hearing screening (UNHS), many children today are diagnosed with HL days after birth (Renee Nolte, 2011). The early diagnosis of HL in newborns and infants has altered how parents deal with HL and the emotions accompanying it (Kurtzer-White & Luterman, 2003). Around 95% of children with HL have parents who have typical hearing and, as a result, primarily have no experience with HL. The dynamic interactions between the child, his or her family, and the larger social milieu generally spearhead a child's development (Mitchell & Karchmer, 2004), all of which are adversely affected by the presence of HL in the child. Families of children with HL also differ in terms of material resources (socioeconomic status), parental resources (parental education, problem-solving skills, mental and physical health, parenting techniques, coping mechanisms), social networks that the family has access to, migration history, and family language (Holzinger et al., 2022), which in isolation or in combination have confounding effects of the rehabilitation of the child with HL.

Best practises in the area of HL mentioned a combination of medical-audiological intervention and the family's involvement in a family-centred early intervention program (Busa et al., 2007; Moeller et al., 2013; Yoshinaga-Itano, 2014). The phrase "family-centred" was initially used by Bronfenbrenner, (1970) to describe a transition from child-centred methods to working with and supporting families in early intervention. Since then, the family-centred practice has received much attention, developed, and strengthened over time. Support that includes the family, who often spend most of the time with the child, is more effective than only child-centred intervention (Espe-Sherwindt & Serrano, 2016). Bronfenbrenner's hypothesis states that parents can effectively connect with their children in a way that fosters their growth if they are given the resources necessary to have the time and energy for their parenting duties (Bronfenbrenner, 1979).

2.1 Understanding parental stress

Everyone experiences stress at some point in their lives. Stress is "a physiological, cognitive, emotional pressure or tension". Stress can build up over time and necessitate action (Lederberg & Golbach, 2002). Parenting a child with a disability results in long-term stress that can negatively impact the child. According to Webster-Stratton (2020), parenting stress is brought on by a mismatch between the demands or pressures of parenting and the resources available to parents (such as psychological health, social support, or cognitive evaluation of a stressor) to satisfy those expectations.

The countless emotions a parent might feel after receiving their child's diagnosis contribute to the complexity of parental stress and emotions such as disbelief, denial, avoidance, grief, anger, worry, and fear (Dogan, 2010; Ellis, 1989; Koester & Meadow-

Orlans, 1990; Luterman, 2008). Stress, as well as a person's intrinsic nature, may both affect psychological health. Studies have identified variables such as personality (Plotkin et al., 2014), sense of coherence (Hintermair, 2004), acceptance (Hintermair, 2004), and self-efficacy (Desjardin, 2003). Chronic pressures can deplete parents' time, energy, and financial resources, potentially leading to emotional reactions such as anger and sorrow (Vukkadala et al., 2019). Mothers of children with a disability may struggle with shame, a sense of helplessness, self-blame, resentment, somatic complaints, depression, withdrawal symptoms, marital problems, child abuse, and perceived failures and anger (Lenhard et al., 2005), parental depression (Gelfand et al., 1992).

The several dimensions that explain parental stress indicate that stress is multifaceted and tremendously impactful in the lives of parents and their children. Thus, parental stress must be investigated due to the wide range of negative consequences it may produce for both parents and children (Pipp-Siegel, 200a).

2.4 Stress in Parents of Children with Communication Disabilities

Many studies have investigated the stress in parents of children with various disabilities (Cuzzocrea et al., 2015; Gupta, 2007; Huang et al., 2013; Park & Lee, 2022). Mothers with autistic children experience more stress and have lower mental health than normal mothers. Social support is a variable that mediates the impact of having an autistic kid on the mother's mental health and the functioning of the family (Montes & Halterman, 2007). Any flaw or delay in a child's social interactions is linked to parenting stress, parent-child relationship issues, and parental discomfort (Waisbren et al., 2004).

According to a study, even parents of children with attention deficit hyperactivity disorder (ADHD) or developmental disabilities (DDs) report higher levels of stress than parents of HIV-positive children, asthmatic children, and children with typical development (Gupta, 2007).

Parental stress in parents of visual impaired child had higher mean scores compared to parents of speech and HI child (Singh & Rani, 2022). In another study by Vijesh (2007), despite variations in child and mother-related characteristics, mothers of both hearing impaired and visually-impaired children experience a moderate level of stress.

2.3 Stress in Parents of Children with Hearing Loss

In recent years, a substantial body of literature has been published on stress in parents of HI children. All of these studies emphasise the importance of considering a wide range of factors outside parental stress when assessing a parent's experience of raising a child. Approximately 90% of infants who are hearing impaired are born to hearing parents (Mitchell & Karchmer, 2004), who often do not have an understanding of the HL and its ramifications in their child. As a result, they encounter several chronic stresses. The clinicians involved in the rehabilitation of child with HL opine that the stress resulting from making potentially life-changing decisions about hearing aids, surgical treatments (cochlear implants), and communication modes (America Sign Language-ASL) are usually made by the parents, which compounds their stress. Other factors in an intervention such as regular visits to Speech therapists, disputes about oral vs manual communication, and educational placement adds up to their stress issues.

It is crucial to recognise that stress is not always static (Meinzen-Derr et al., 2011). Stress levels among mothers of hearing impaired children are not significantly

greater than those of mothers of hearing children (Pipp-Siegel, 2002; Stuart & Moretz, 2000). Additionally, Meadow-Orlans (2016) discovered no changes in parental stress levels between hearing impaired groups of 9-month-old babies with mild-to-profound hearing loss. (Quittner et al., 1990) stated that parents of HI children experience more overall stress than parents of children with normal hearing. According to Lederberg & Golbach (2002) mothers of 23 children with severe-to-profound hearing loss experienced higher stress than mothers of hearing children. Not only mothers of the children with HL, but it affects the emotional well-being of all the family members (Koester & Meadow-Orlans, 1990). As per Ellis (1989), a HL diagnosis might be perceived as a family crisis. They must restructure their lives and accept the effects of the child's HL on previously set expectations. Audiologists must therefore recognise that a HL diagnosis can affect the whole family and include them in the family-based intervention.

2.4 Factors Affecting Parental Stress

Certain variables might increase the level of stress experienced by hearing parents when parenting a child with HL. By investigating this, one may better understand the complexities of parental stress and the impact that various aspects have on stress levels. According to Pipp-Siegel et al. (2002), a parent's stress level is increased by demographic features of the child, variables connected to the child's hearing loss, and characteristics and perceptions of the mother. Furthermore, other factors such as the presence of other impairments and those connected to the child's parents, such as family income (Puff & Renk, 2014; Quittner et al., 1990), daily hassles of parenting, and support, can all have a detrimental influence on parental stress levels (Pipp-Siegel et al., 2002).

2.4.1 Child characteristics

2.4.1.1 Age of the child

Konstantareas & Lampropoulou (1995) discovered that when other factors were controlled, maternal stress increased with the child's age. It was discovered that mothers of older children reported higher stress levels than mothers of younger children. In contrary, Pipp-Siegel et al. (2002) suggested that when other variables are controlled, no relationship between parental stress and the child's age. A longitudinal study by Lederberg et al. (2002) evaluated the parental stress and social support in hearing mothers of children with HI across three years (22 months, 3 and 4 years old). When children were 22 months old, mothers of children with HI compared to mothers of hearing children raised more concern about their children being less self-sufficient and having poor communication skills. As measured by the parenting stress index (PSI) when their children were 3 and 4 years old, mothers of hearing and HI children did not report significantly different levels of overall parenting stress. While Quittner et al. (1990) discovered a significant degree of stress on PSI for mothers of hearing-impaired pre-schoolers, Meadow-Orlans (2016) and Pipp-Siegel et al. (2002) showed no differences in stress as measured by the PSI throughout infancy and toddlerhood (2-3 years of age).

Stress related to scholastic performance has inevitably increased during the school age of the child (Neece et al., 2012). Following the diagnosis of hearing loss, stress related to the need for support and equipment also grew over time. It's possible that when parents grow more aware of their HI child's demands, particular devices (such vibrating alerts) might become crucial (Meinzen-Derr et al., 2008). In contrast, stress related to medical conditions lessened with time. The first high levels observed in the

initial stages may be due to the numerous related appointments, starting therapies, and feeling at ease with professionals following the diagnosis. It was observed that stress in this area lowers when families grow accustomed to certain parts of clinical treatment. Communication-related stress persisted across groups, but marginally less for the group with a 60-month duration (Meinzen-Derr et al., 2008). This research confirms a concern shared by many caregivers about how HI affects communication and the family as a whole.

2.4.2 Factors Related to Hearing Loss of a child.

2.4.2.1. Degree of hearing loss

Examining a child's degree of HL, age of identification, language abilities, and mode of communication, in particular, might be beneficial. The degree of HL has been investigated for a possible relation to parental stress (Pipp-Siegel, 2002). This study discovered that mothers of children with a mild degree of HL had more stress than mothers with a higher degree of HL, indicating that a lesser degree of HL generates more parental stress. They discovered that hearing mothers of children with less HL suffered higher stress, as parents underestimate the impact of milder hearing loss on the child's functioning.

2.4.2.2 . Age of diagnosis

Parents of children who receive prompt diagnosis and supportive care report stress levels that are within the normal range (Lederberg & Golbach, 2002) . Depending on the age of diagnosis, when compared to parents of children with hearing loss diagnosed less than 24 months or during the first 24 to 60 months, parents of children diagnosed with HL more than 60 months reported higher levels of stress over

educational components of their child's requirements (Pipp-Siegel et al., 2002). Parents of children diagnosed with HL within 24 months reported feeling more stressed about healthcare than parents of children who had the diagnosis more than 24 months earlier (Pipp-Siegel, 2002). Additionally, in the specific context of Early Hearing Detection and Intervention, the impact of the age of HL detection on parental stress has been intensively researched. According to the study, there were no modifications to maternal bonding and attachment or an increase in parental stress related to an earlier age of HI identification (Pipp-Siegel et al., 2002).

2.4.2.3 . *Age of intervention*

Early intervention appears to be the most effective stress reduction approach for parents of HI children (Hintermair, 2006). Young and Tattersall (2007) suggested that having the chance to adjust to their child's requirements at a young age and having the chance for earlier intervention helped to lessen the parents' suffering, grief was partially offset by the early intervention.

2.4.2.4 . *Language Delays*

Elevated stress levels were reported among parents of children with HL with lower language abilities or greater rates of behaviour problems (Blank et al., 2020; Quittner et al., 2010; Topol et al., 2011). According to Lederberg & Golbach (2002), language is not an essential aspect of communication during the infant stage. Hence there is less evidence of the impact of hearing loss. However, as the child grows older and language delays become more common, the parents may feel the impact of the hearing loss, which can manifest as grief or anxiety. Hintermair (2006) also illustrates that a child's communication skills can influence parental stress, which in turn may influence the child's development.

2.4.2.5 . *Based on the intervention device*

Studies with conflicting results were reported. According to Horsch (1997), when intervention approaches are compared, parents of children who use cochlear implants (CI) have stress levels that are equivalent to those of parents of children with normal hearing, while parents of children who use hearing aids (HA) experience more stress. According to Prakash et al. (2013), Parents of children with CI and those who use HA experienced higher levels of stress, although the CI group experienced these levels at a higher rate. However, in another research, parents of HA-receiving children expressed less stress and concern than those of CI-receiving children (Mahmudi et al., 2017). Mothers of children fitted with CI also reported an improvement in their overall maternal health (Gohari et al., 2020). A recent study evaluating the quality of life in parents of children with CI and HA found that on several psychosocial variables pertaining to functional, social, and psychological well-being, parents of children with HA and CIs appear to be similar (Mundayoor et al., 2022).

2.4.3 Family Characteristics

2.4.3.1 Socioeconomic status

Hearing loss can place a significant social and financial hardship on families. According to Yucel et al. (2008), the main variables that may prolong the time between amplification and intervention are the family's poor socioeconomic situation, their lack of knowledge, and the difficulties they experience in getting a hearing aid device due to financial constraints (Yucel et al., 2008). Pipp-Siegel et al. (2002), in their study, concluded that mothers with lower incomes reported feeling more stressed. Similar effects of poor income negatively impacting parental stress were discovered by (Puff &

Renk, 2014; Quittner et al., 1990). Several studies found that economic and parental difficulties faced by mothers and fathers are crucial predictors of each child's distinctive emotional and behavioural functioning (Jackson et al., 2000; Parke et al., 2004; Robila & Krishnakumar, 2006).

2.4.3.2 Acceptance and coping mechanisms

Acceptance is characterised by the capacity to confront what an event or scenario has to give without attempting to avoid it. In other words, discard dysfunctional agendas by taking stock of the circumstances, including the obstacles, restrictions, and resources, and focusing on making the best of the possibilities while engaging in an active process of effective coping (Blackledge & Hayes, 2001; Walsh, 2003).

Families' personal and social coping mechanisms for dealing with stressors and obstacles have an impact on how well they adapt to the many challenges brought on by childhood hearing loss (Moeller, 2000). Parents who struggle to accept their child may reject their child's special needs (Lloyd & Hastings, 2008). In particular, evidence supports the notion that early assistance and enhanced parental coping mechanisms during this period might mitigate these detrimental effects (Pipp-Siegel et al., 2002). It has been suggested that accepting the child and his/her disability is a positive "stage" in family adjustment and enables parents to meet their child's needs (Kandel & Merrick, 2007) which would reduce stress among parents of HI children (Zaidman-Zait, 2007). A family's ability to accept their child's impairment, cope according to it, and meet the child's needs may have a significant positive impact on the child's wellbeing and social, emotional, and language development (Calderon, 2000; DesJardin & Eisenberg, 2007; EB Cole, 2007).

2.4.3.3 *Self-efficacy*

Parental self-efficacy (PSE), drawn from Bandura (1982) explanation of self-efficacy in the Social Cognitive Theory, refers to parent's perceptions about their capacity to successfully act in their parenting role to raise children (Bandura, 1982; Coleman & Karraker, 2003; Jones & Prinz, 2005). It is influenced by several factors, including (a) the parent's personal and psychological resources, (b) the child's characteristics (such as temperament and the presence/absence of behavioural issues); and (c) the environmental context (Belsky, 1984; Bloomfield & Kendall, 2012; Jones & Prinz, 2005).

In the case of parents with HI child, general self-efficacy refers to the belief in one's capacity to perform competently as a parent in the setting of early intervention involvement. Specific self-efficacy relates to a parent's capacity to manage the obstacles connected with childhood HL, such as providing sensory aids or assisting the child's language development (Bandura, 2006). It was discovered that mothers' stronger self-efficacy in helping their child's speech and language development improved the child's language acquisition (Desjardin, 2003; DesJardin & Eisenberg, 2007). As a result, it is critical to understand both general and specific self-efficacy in parenting a HI child.

2.4.3.4 *Social Resources*

Studies have discovered that social support is crucial in moderating parental stress. The wellbeing and competence of parents to deal with their child's deafness depends heavily on social support (Dirks et al., 2016; Lederberg & Golbach, 2002; Meadow-Orlans, 2016; Oelofsen & Richardson, 2006; Pipp-Siegel, 2002). Hintermair (2006) defines social resources as the assistance that hearing parents of hearing-impaired children receive from their natural and artificial networks. Natural networks

include spouses, children, parents, relatives, acquaintances and friends. Artificial networks are new contacts with other parents in a similar situation, such as parents in a parent group and interaction with HI people and professionals.

As per Lederberg & Golbach (2002), having a child with HI may have a variety of effects on a mother's social networks. It was reported that mothers of hearing-impaired children had smaller social networks (Quittner et al., 1990). Additionally, the level of support given to mothers have a substantial impact on the effectiveness of mother-child interactions (MacTurk et al., 1993), which has been linked to more remarkable language development in preschool-aged children (Pressman et al, 1999). According to some researchers, spousal support is the most significant predictor of parental stress in all families, with parents in unhappy marriages expressing the most anxiety (Deater-Deckard & Scarr, 1996). It has been discovered that regular family and friend involvement in offering knowledge, practical assistance, and emotional support helps parents cope with raising their hearing impaired child (Eyalati et al., 2013).

2.5 The Impact of Parental Stress on the Child with Hearing impairment

For parents of HI child, handling their child's diversified needs are challenging (Prakash et al., 2013). In HI children's intervention, the development of emotional, social, intellectual, and language skills are facilitated by parental engagement (Calderon, 2000; DesJardin & Eisenberg, 2007; Hintermair, 2006; Holzinger et al., 2020; Kurtzer-White & Luterman, 2003; Sarant & Garrard, 2014). According to several studies, parental stress will have a negative impact on the language development of HI children (Hintermair, 2006; Pressman et al, 1999), leading to increased child behaviour problems (Pipp-Siegel et al., 2002) and lower quality of the child's self-esteem (Sardar & Kadir Dr., 2012). Another study focused on 164 young children at least three years

of cochlear implant use, focused on possible mechanisms by which parenting stress affects spoken language outcomes and discovered parental self-efficacy as a mediator to account for 43 per cent of this relationship (Cejas et al., 2021). Hence, parental stress can have a range of impacts on a child with hearing impairment. In order to prevent or minimise its influence on the child, it is crucial to identify these stresses at the earliest.

2.6 The Professional's Role in Addressing Parental Stress

As technology advances, the role of experts in the rehabilitation of HI child and counselling their parents evolves. The success of any auditory rehabilitation intervention program for HI children requires skilled professionals and a high degree of commitment and involvement from the parents (Nelamegarajan et al., 2021). According to Koester & Meadow-Orlans (1990), families of early HI children frequently count on experts working in intervention programmes to be a part of their support system. Professionals should develop an accepting and positive environment in which parents may work through their grief and emotions (Luterman, 2017) and should complement and improve the parent's resources. Additionally, understanding trigger events leading to the reoccurrence of negative emotions will help prepare parents for such situations and develop coping strategies owing to the better language and social-emotional outcomes in children with HL (Meinzen-Derr et al., 2011; Moeller, 2000; Stika et al., 2015; Yoshinaga-Itano, 2003). Professionals must continue reaffirming to parents that they are respectable individuals while encouraging and facilitating contact with others in similar situations (Ellis, 1989). Professionals should also promote father's involvement while remaining sensitive to families' needs and preferences.

2.7 Assessment of Stress in Parents with Hearing Impaired child.

2.7.1 Close-ended questionnaires assessing parental stress

Given that audiologists frequently interact with the parents of children with HI, it is imperative to emphasise the significance of assessing family stress and implementing family-centred interventions. There are several questionnaires to assess parental stress and their quality of life -Parenting Stress Index, Fourth Edition Short Form (PSI 4) (Abidin, 1995), caregiver strain questionnaire, The Early Intervention Parental Self Efficacy Scale (EIPSES) (Guimond et al., 2008). Differences in how parental stress is measured are one of the main causes for variability in self-reported questionnaires (Blank et al., 2020).

Several investigations used the PSI, tapping on general parental stress (Åsberg et al., 2008; Lederberg & Golbach, 2002; Meadow-Orlans, 1994; Pipp-Siegel, 2002 p; Quittner et al., 1990; Sarant & Garrard, 2014). Several other studies have used questionnaires (e.g., Family Stress Scale: Quittner et al. (1990); on resources and Stress: (Friedrich, 1983), one that assesses the challenges of raising a child with HL in the context of parenting (Blank et al., 2020; Lederberg & Golbach, 2002 1; Quittner et al., 1990, 2010; 1991). Studies that use context-specific parenting stress assessments seem to be more reliable in detecting higher caregiver stress levels in family with a HI child. These surveys are probably sensitive to capture the distinct and particular parental stressors due to long term deficit in children resulting in language delay and communicative incompatibilities between them (Quittner et al., 2010). Although these questionnaires can tap only into a few aspects of parental stress-related problems, most of them are not validated for all socioeconomic, educational backgrounds and ethnic populations. In contrast, the biopsychological perspective may be more pertinent to comprehensively document the social and psychological impact on parents of children with HI. These impacts can be highlighted under different categories of the International classification of functioning, disability and health (ICF) theoretical

framework (WHO, 2001). Using open-ended questions to elicit responses, ICF coding gives a comprehensive understanding of global issues.

2.8 International Classification of Functioning, Disability and Health (ICF)

Classification of health components concerning a person's experience has emerged during the past four decades. In the early 1970s, the imperfection of the International Classification of Diseases (ICD) has been confessed by the World Health Organization in describing the effects of non-acute diseases. As a result of this confession, the International Classification of Impairment, Disability and Handicaps (ICIDH) was developed to explain and classify disabilities (WHO, 2001). The ICIDH was identified as progress in rehabilitation contexts as it focused on the consequences of diseases. Unluckily, the ICIDH also failed to include the experiences of disability groups (Schneidert et al., 2009). In the mid-1980s, a revision of the ICIDH was initiated, which resulted in the development of updated versions of the ICIDH, lastly designated the International Classification of Functioning, Disability, and Health (ICF) in 2001 (WHO, 2001). The broader perspective of a person's health can be assessed from information on diagnosis plus information on functioning.

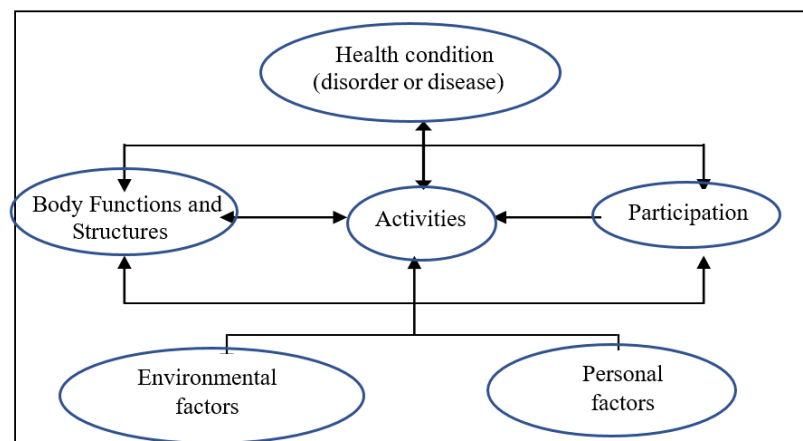
The International Classification of Functioning, Disability and Health (ICF) is both a classification and a conceptual model used when describing features related to health, such as human functioning or disability. It does not classify people but instead represents the health situation of persons with health conditions, i.e., the health and health-related states associated with all health conditions can be described using the ICF. The ICF is based on a bio-psycho-social approach to functioning and health. The concept is developed concerning the perspective of the body, the individual and the society, and also it represents the opposite designations functioning and disability.

The classification describes human functioning with the positive concepts of body functions, body structures, activities, and participation. Disability, in the ICF, is defined with the negative terms impairments (i.e., problems in body structures or functions), activity limitations, and participation restrictions. Accordingly, disability is described in terms of functioning, i.e., when the level of functioning is ‘below a determined threshold along a continuum for a specific health domain (Bickenbach et al., 2012), functioning becomes a disability. Moreover, ICF explains the external factors, i.e., (Contextual factors) to understand human functioning and disability better. This context in the ICF is described as environmental factors and personal factors. Hence, the ICF is multidimensional, mentioning the importance of both internal and external influences on human functioning and disability.

2.9. ICF – A Conceptual Model

Figure 2.1

Interactions Between the Components of ICF (WHO, 2001)



The ICF is an interactive model in which each factor can influence others in a complex way of interactions. A fundamental standpoint in the model is the non-causal relationship between different components (Cieza et al., 2008; Cummins et al., 2010). Though functioning is associated with a health condition, it is not always viewed as a

direct consequence. Instead, it is a consequence of a complex interaction between the health condition and contextual factors (Bickenbach et al., 2012).

2.9.1 Activities & Participation

Activity is defined as "the execution of a task or action by an individual and should be evaluated regarding the nine life domains outlined in the ICF" (e.g., communication, interpersonal interactions and relationships, major life areas). Because participation and activities overlap these life domains, any of the two ideas may be present in any given domain. An activity restriction is a challenge that a person encounters when doing a task or action (WHO, 2001).

‘Participation’ is closely connected to the activity, defined as ‘involvement in a life situation. The problems that an individual may experience in the involvement in life situations are denoted as participation restrictions. Participation in a life situation means ‘taking part’, ‘being included’ or ‘being engaged’ in an area of life (WHO, 2001).

2.9.3 Body functions & Body structures

Located to the left in the model are the dimensions of body functions and body structures. Body functions refer to the physiological processes of body systems (including psychological functions), whereas body structures are the anatomical parts of the body (organs, limbs). The negative aspect of these two concepts is denoted as the shared notion of ‘impairment’.

2.9.4 Contextual factors

Environmental factors and personal factors are two ICF contextual aspects that may have an impact on a person's health if they have a health condition. The real

localization in regard to the individual, with environmental factors being considered as external elements to the individual, is the major distinction between these two components. In contrast, personal factors are internal. Personal factors are characteristics of an individual that are not related to a health condition or state of health. They represent the specific context in which a person lives and works. These variables may include factors like gender, race, age, other health issues, level of fitness, way of life, habits, upbringing and coping mechanisms (WHO, 2001). Environmental factors in the ICF are viewed as human-related, i.e., social and attitudinal, or physical (WHO, 2001). Environmental factors are always viewed as having a favorable or negative impact on a person's performance in the particular circumstance specified, and are therefore either referred to as facilitators or hindrances/barriers. The individual environment, often known as the natural environment or the "face-to-face" environment, is one way to define environmental factors that an individual may encounter with. On the other hand, they also comprise the societal environment, which is defined as the formal and informal structural systems that constitute the setting in which individuals reside (WHO, 2001).

2.10 ICF –Classification

As a whole, ICF classifies health conditions into two parts: (i) functioning and disability; and (ii) contextual factors. These two parts are further subdivided into the following components: body functions, body structures, activities and participation, environmental factors, and personal factors (Schneidert et al., 2009). The physiological functioning of body systems is included in body function, such as sound detection. In contrast, anatomical parts of the body are included in the body structures (e.g.) Ear, heart. The execution of a task or action by an individual and participation comes under the activities. Environmental factors contain the physical and social environment where

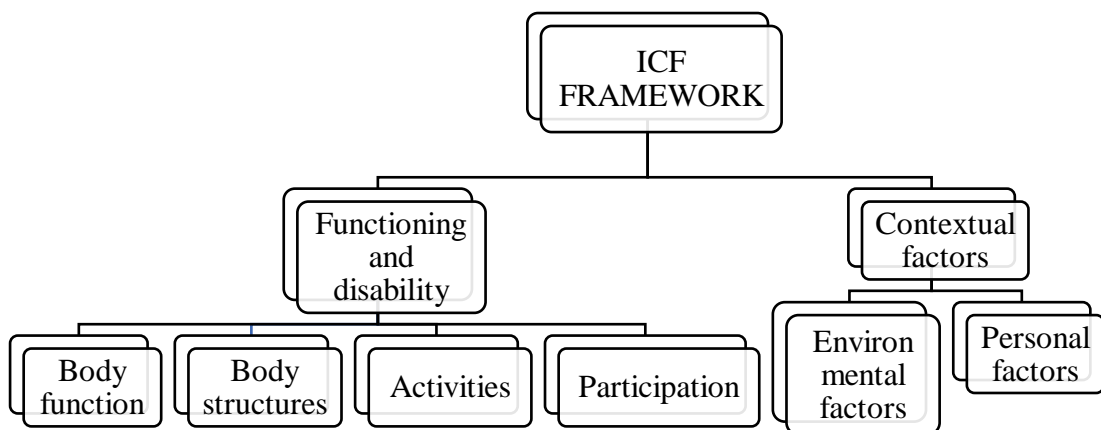
people live (e.g.) family support and relationship. And, the intrinsic part of the individual not associated with the health condition is related to the personal factors (e.g.) Age, gender.

Figure 2.2

ICF framework and Its Domains

2.11 ICF Core Sets

The WHO launched the ICF core sets initiatives to enhance the ability to apply ICF in clinical settings or research. (Bickenbach, 2012; Stucki & Grimby, 2004). In total, the ICF model contains over 1500 categories, which makes its implementation in clinical



practice and research challenges. To address this challenge, ICF Core Sets have been developed. ICF Core Sets include the ICF categories that are most relevant for describing the functioning of persons with specific health conditions. A core set is a set of ICF categories of particular relevance for a certain diagnosis or health condition. Core sets have been developed for various conditions. There are two kinds of core sets: comprehensive core sets, consisting of all ICF categories relevant to the specific area, and brief core sets, which are more compressed versions of the comprehensive core sets (Selb m, 2015). Until 2017, 35 core sets for different health conditions, circumstances,

situations, and generic core sets have been developed (Stucki & Bickenbach, 2017). In 2008, an ICF core sets project targeting adults with HL was initiated (Danermark et al., 2010). In other core set projects, several other types of outcome measures have been identified when targeting the researcher perspective, such as standard provider-reported or third-party-reported measures (e.g., clinician assessments), nonstandard measures (e.g., single questions, Escorpizo et al., 2011), clinical measures (e.g. joint pain or joint swelling), and technical measures (e.g. X-ray, Zochling et al., 2006).

In conclusion, ICF is beneficial for purposes other than assessing population health. With ICF, it is possible to discover environmental variables that have an influence on involvement in sectors like education, transportation, or housing, as well as potential health determinants (Cerniauskaite et al., 2011). A greater understanding of parental stress may be gained by including ICF rather than solely utilizing open-ended questions.

Chapter III

METHODS

3.1 Research design and Participants

A prospective study design with purposive sampling, involving within group comparison was carried out in the study (Schiavetti & Metz, 2005). Parents of children with hearing impairment (HI) attending therapy at AIISH were included in this study. A total of hundred parents of children with HI were contacted through telephone to request their participation by explaining the purpose of the research and scrutinising for their inclusion criteria. Informed consent was obtained through the form (attached in g-mail and WhatsApp or by contacting through telephone) before the start of the study. The parents who voluntarily agreed to participate in the survey and at least studied English until VII grade were asked to fill up a questionnaire sent via WhatsApp or Gmail. The responses were collected directly through telephone conversations for parents who had difficulty filling up the questionnaire.

3.2 Inclusion Criteria

Only mothers of children with bilateral profound congenital hearing loss aged between 4-6 years were included in the study. All the mothers included in the study did not complain or had any history of psychological illness. The other inclusion criteria related to the children whose mothers participated in the study are: all the children had attended listening training for at least 1 years (not more than 3 years), whose age of identification was less \leq 2 years, with the initiation of rehabilitation procedure before 3 years of their chronological age.

3.3 Exclusion criteria

- Parents of children with multiple disabilities.
- Parents with more than one child with hearing impairment.

- Parents who had psychological issues before the birth of a hard of hearing child.

Table 3.1.

Demographic Information of the Participants in the Study.

Demographic information	Mean (SD)
Sample size (n)	100
Mean age of child (in years)	5.08 ± 0.84 SD
Mean age of mother (in years)	28.93 ± 4.12 SD
Education	
Illiterate	3
Primary education	34
Till Higher education	30
Undergraduate	25
Postgraduate	8
Socioeconomic status	
<10,000	25
10,000-25,000	42
25,000-40,000	30
>40,000	3

Note. SD = Standard Deviation

3.4 Ethical considerations

In the present study, all the testing procedures were carried out on humans using non-invasive techniques, adhering to the guidelines of the institutional research advisory board on ethical standards (Basavaraj et al., 2009). The approval from the institute's ethical committee was also received before conducting the study. All the

procedures were explained to the participants, and informed consent was taken from all the study participants.

3.5 Procedure

The study was conducted in two phases.

3.5.1. Phase I: Obtaining responses to surveys. The survey consisted of four sections given in section 1 of Appendix I (Consent form, demographic details, obtaining responses to two open-ended questions, obtaining responses to Caregiver Strain Questionnaire: CGSQ). The parents were given two options for the survey: answer these questions with the google form link or answer through the mobile phone. The mobile conversations were recorded and later transcribed verbatim. The open-ended questions used in the study were adapted from Granberg et al. (2014). These questions were formulated based on the different International classification of functioning, disability and health (ICF) components that will cover participants' perspectives on aspects of the disability and the effects of their child's HI on their daily lives. The questions asked were:

Problem Question (PQ). Make a list of problems or challenges you have faced due to your child's HI. List as many as you think of.

Life Effects Question (LEQ). Please state the effects of your child's HI on your day-to-day life. List all the effects, as many as you can.

Answers to these open-ended questions can elicit responses that can be coded based upon the different ICF components: body structure and functions, activities & participation, environmental factors, and personal factors that will cover participant's perspectives on aspects of the disability and the effects of their child's HI on daily life. The answers obtained for the above two questions (PQ & LEQ) were given to the three

native Kannada and Hindi speakers and translated into English. A translation that 2/3 of native speakers agreed upon was used in the study. These answers were also reverse translated from English to Kannada or Hindi to see for translation errors (if any). Those samples with > 10 % of non-agreement in reverse translation were excluded from coding.

3.5.1.1 Caregiver Strain Questionnaire: CGSQ

The Caregiver strain questionnaire (CGSQ) is a 21 item self-report instrument for assessing caregiver strain in parents of children and adolescents with significant emotional and behavioural problems. This questionnaire was modified to extend its application related to hearing impairment by replacing emotional/behavioral domain with hearing problems. It has a set of questions (1-10 items) focusing on family and rest of the items deriving responses asking about oneself. It consists of three dimensions to assess the caregiver strain: Objective caregiver strain, subjective care giver strain (APPENDIX I, section 3).

The objective caregiver strain dimension comprises of questions that can identify negative outcomes from parenting a child who had emotional or behavioural issues. This 1 included 11 items: interruption of personal time; missing work or neglecting duties; child getting into trouble with the community; family member(s) having to do without things, suffering mental or physical health effects, or receiving less attention; financial strain; social isolation; and disruption of family routines, relationships, or social activities.

The second dimension subjective caregiver strain has two divisions-scales: internalised and externalised caregiver strain sub-scales. The internalised subjective caregiver strain dimension tapped the feelings that the caregiver internalised as a result

of caring for a child with an emotional or behavioural disorder. This subscale included six items: feeling sad or unhappy, worrying about the family's future, worrying about the child's future, feeling guilty, tired and strained, and sensing that the family had taken a toll. The externalised subjective caregiver strain factor is associated with negative emotions toward the child. This subscale was made up of four items: resentment, anger, embarrassment, and relating poorly with the child.

The respondent is asked to rate the severity of each event or emotion as a result of their child's issues during the previous six months. Responses are graded on a 5-point scale, from not at all to very much of a problem.

3.5.2 Phase II: International Classification of Functioning, Disability and Health (ICF) coding and Caregiver Strain Questionnaire scoring.

International Classification of Functioning, Disability and Health (ICF) coding.

All the data were linked to the ICF framework with the help of an analysis method developed and referred to as the 'seven steps linking procedure' (Hsieh & Shannon, 2005). The seven steps are (1) meaningful unit identification, (2) defining the significant concept(s), (3) underlying meaning interpretation, (4) determining the linking unit(s), (5) appropriate ICF category derivation, (6) documenting the linking rule applied, and (7) verifying the representativeness of the ICF categories chosen.

ICF classifies information into two parts: (i) functioning and disability; and (ii) contextual factors. These two parts are further subdivided into the following components: body functions, body structures, activities and participation, environmental factors, and personal factors (Schneidert et al., 2009). For example, anxiety reported by parents is one of the aspects of Body Function which comes under Emotional functions.

The transcribed responses were given to 3 ICF coders, who were asked to code all the responses separately. The coding by 3 ICF coders was carried out to improve the reliability of the coding process. The codes which were agreed upon by 2/3 coders were retained. If there was any disagreement in the coding, it was discussed between the coders, and a final consensus was obtained. Based on the final code, the number of codes for each participant for PQ and LEQ and total (PQ + LEQ) were determined. The codes were grouped under the following ICF categories: body functions, activity limitations and participation restriction, environmental factors, and personal factors. For example, anxiety (b1522) reported by parents is one of the aspects of body function. It comes under Specific mental functions (b140-b189), within Emotional functions (b152) then specifically under range of emotion (b1522).

Caregiver Strain Questionnaire scoring. A score of 1-5 is given for each question and the mean of the questions for each subscale of CGSQ, is calculated as follows:

Objective strain - mean of items 1-11

Subjective externalized strain – mean 13, 14 (reverse coded), 15, 19

Subjective internalized strain - mean of items 12, 16, 17, 18, 20, 21

Global score – sum of the three subscale scores

3.5.3 Statistical Analyses.

The data obtained was tabulated and analysed using IBM statistical package for social sciences (SPSS), Version 26.0 software (IBM Corp, Armonk, NY, USA) and GraphPad Prism V9 software (version 9.3.1 for Windows, GraphPad Software, San Diego, California USA). The data coded were tabulated and analysed. Descriptive statistics for means and standard deviation (SD) were obtained using SPSS, Version 26.0.

The total number of responses for the PQ and LEQ questions was obtained. An inter-rater reliability check was carried out using Bland-Altman agreement analysis. This analysis was carried out for combined scores (PQ + LEQ) of the following domains: body function (BF), activity limitation and participation restriction (AL), and environmental factors (EF). In addition, Bland–Altman agreement analysis was also done on the composite score (BF, AL and EF). The difference in the coders' ratings against the average ratings in all the above domains of ICF was compared. The inter-rater difference ratings beyond the limits of agreement (± 1.96 standard deviation) were analysed to determine the errors (Giavarina, 2015).

After determining the agreement between the coders, the normality check was performed using Shapiro Wilk's test and this study's data were found not to be normally distributed ($p < 0.05$). Based on the results of the normality test, the frequency of the ICF codes within each category of ICF classification was counted for each participant, for both the problem and life effect questions and question-wise differences in these counts was analysed using Wilcoxon signed rank test. The close ended CGSQ items were analysed for any correlation with the open ended ICF questionnaire domains using spearman rank test.

Chapter IV

RESULTS

The present study was carried out to examine parental stress in parents of children with Hearing Impairment (HI) using International Classification of Functioning, Disability and Health (ICF) and Caregiver Strain Questionnaire (CGSQ). The participants were 100 parents of children with HI, and they were given two open-ended questions. The responses to the two open-ended questions were collected through a phone call which was recorded and transcribed verbatim. The keywords in the transcribed responses were identified and converted to ICF codes with the help of trained coders. The responses to CGSQ were scored according to sub-scales for each participant. Descriptive and inferential statistics were carried out using SPSS (version 26.0) software. Shapiro Wilk's test of normality was done to check whether the data is normally distributed or not, and this study's data were found to be non-normally distributed ($p < 0.05$). Hence, non-parametric inferential statistics was carried out for further analysis. The results of the study are explained in the following headings:

4.1 Inter-Coder reliability estimation

4.2 Quantification of problem and life effects of parents of children with HI

4.3 Impairment of Body Function

4.4 Activity Limitations and Participation Restrictions

4.5 Environmental factors and personal factors

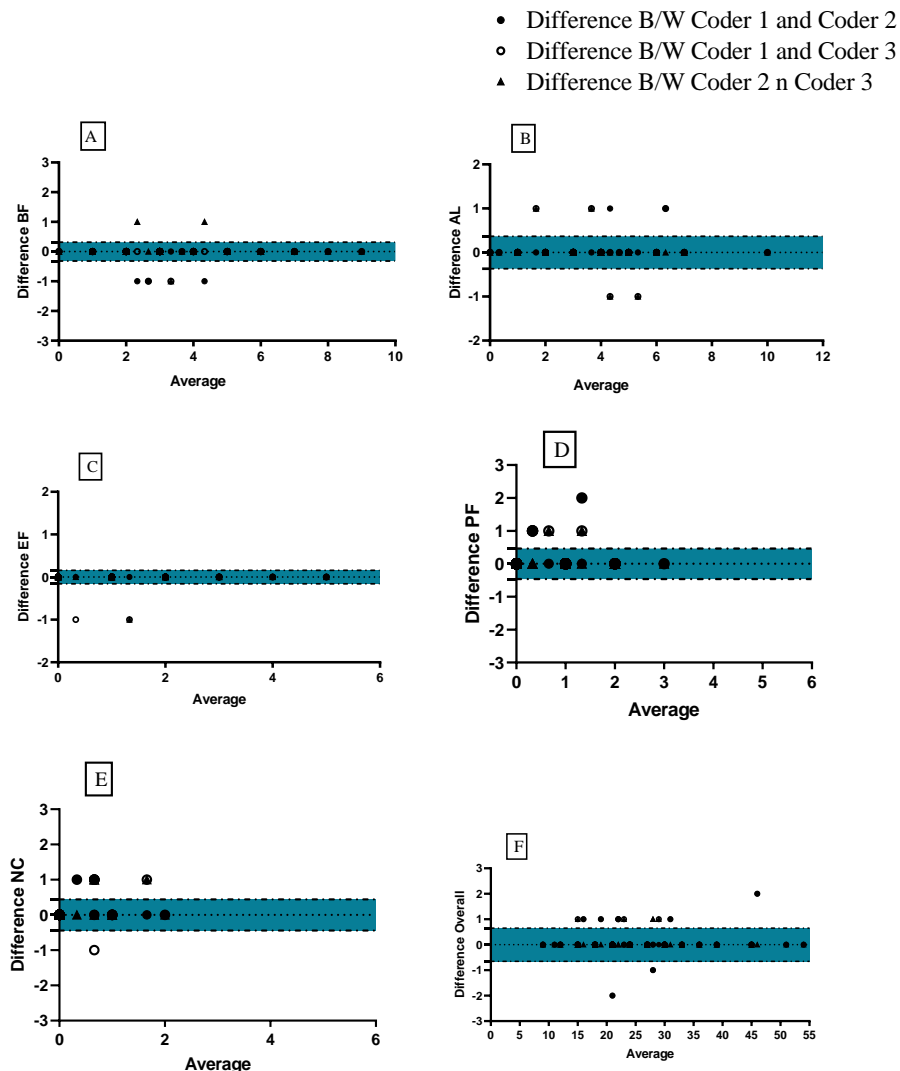
4.1 Inter-Coder reliability estimation

The results of the modified Bland-Altman plot depicting the average of the total codes on the x-axis and the difference in total frequency of coder ratings (1 vs 2; 2 vs

3; 1 vs 3) on the y-axis is shown in Figure 4.1 (A-F). The blue shaded area denotes the limits of acceptable agreement which is ± 1.96 SD. On visual inspection of the Bland-Altman plot, it is apparent that most of the overall frequency of the coders (276 on 300, i.e., 100 observations*3 coder differences) fell within the limits of variance (blue shaded area in Figure 4.1 F). The analyses of the outliers in Figure 4.1 (F) showed that 24 out of 300 observations did not correlate well, accounting for an error of 8.00 %. The percentage of inter-rater reliability in overall scores was approximately 92.00 %, indicative of high reliability in the inter rater codings for overall responses. Similarly, Bland-Altman inter-rater agreement analyses for domain wise codings indicated a biasing error of 2.66% (8/300), 3.66% (11/300), 1.00 % (3/300), 4.66% (14/300) and 5.33% (16/300) for combined scores (PQ and LEQ) of body function (BF, Figure 1A), activity limitation and participation restriction (AL, Figure 1B), environmental factors (EF, Figure 4.1 C), personal factors (PF, Figure 4.1 D) and non-codable (NC, Figure 1E). The corresponding inter-rater reliability was 96.83%, 95.64%, 98.8%, 94.45%, 93.66% for each category discussed above.

Figure 4.1. Bland-Altman Plot depicting inter-rater variability for each ICF category A) Body function, (B) Activity limitation and participation restrictions, (C) Environmental factors, (D) Personal factors, (E) non-codable, and (F) Overall.

The blue shaded area shows the limits of agreement (± 1.96 SD)

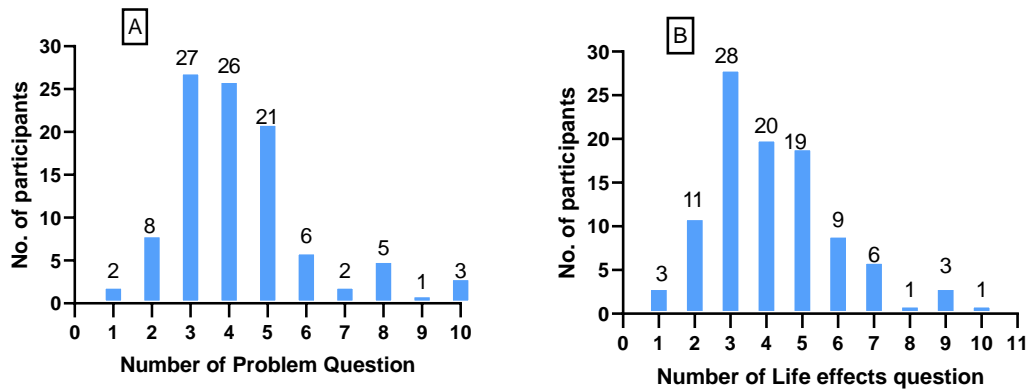


4.3 Quantification of problem and life effects of parental stress

4.2.1 Number of responses

A total of 862 codes were obtained, out of which 437 responses were for problem question, 425 responses for life effects question. Thirteen codes were not codable under ICF. The number of meaningful responses ranged from 1 to 10 as shown in Figure 4.2.

Figure 4.2. The bar graph depicting the number of problems listed in (A) Problem Questions and (B) Life effect Questions



The number of meaningful responses ranged from 1 to 10, and most of the participants provided 2-6 meaningful responses for both the questions, as shown in Fig. 4.2. The overall mean number of responses per participant was 4.28 and 4.22 for PQ and LEQ, respectively. No significant differences were observed in the total number of responses between the two questions, as seen in Table 4.1. However, when each of the category was analysed separately, significant differences (p ranging from 0.01 to <0.001) were noticed between the PQ and LEQ responses. The LEQ median scores were significantly higher ($p < 0.001$) in body function, while the PQ median scores were significantly higher ($p < 0.001$) for activity limitations and participation restriction (Table 4.1). The descriptive analyses (mean & median) analyses revealed that participants had experienced equivalent difficulties in PQ and LEQ (Table 4.1, with few categories showing more significant ($p < 0.05$) PQ problems (Activity limitations and participant restrictions, environmental factors while other category had more significant LEQ problems (body function, personal factors)).

Table 4.1.*Number of Responses in Each of the ICF Domains Listed in the Two Questions*

	PQ Mean (\pm one SD)	PQ Median (IQR)	LEQ Mean (\pm one SD)	LEQ Median (IQR)	Wilcoxon (/Z/)	Sig. (<i>p</i>)	Effect size <i>r</i> = (/Z// \sqrt{N})
All responses	4.28 (1.71)	4.00 (2.00)	4.22 (1.82)	4.00 (2.00)	0.27	0.79	0.18
Body function	1.16 (1.00)	1.00 (2.00)	2.02 (1.24)	2.00 (2.00)	4.72	< 0.001	0.42
Activity limitations and participation restriction	2.15 (1.25)	2.00 (2.00)	1.45 (1.12)	1.00 (1.00)	4.23	<0.001	0.42
Environmental factors	0.67 (0.79)	0.00 (1.00)	0.3 (0.59)	0.00 (0.00)	3.75	<0.001	0.37
Personal factors	0.22 (0.48)	0.00 (0.00)	0.43 (0.63)	0.00 (1.00)	2.37	0.01	0.13
Non coded	0.09 (0.28)	0.00 (0.00)	0.02 (0.14)	0.00 (0.00)	2.11	0.35	0.13

The descriptive (mean and median) analyses of the frequency count for overall responses revealed that participants had experienced more difficulties in PQ than LEQ (Table 4.1), although they were not reaching statistical significance ($p > 0.05$). On overall frequency count, most of the problems and the life effects confronted by parents of children with HI were linked to activity limitations and participant restrictions (358/862), followed by body function (321/862) and environmental factors (103/862).

4.2 Impairment of body function

Body function restrictions were affected second most frequently in parents with HI children. The frequency of each code in body structure and function is shown in

Table 4.2. There were 321 responses, with 121 responses from PQ and 200 from the LEQ. The most frequently occurring category was Emotional functions b152), other frequently occurring categories included: Range of emotion (b1522), Problem-solving (b1646), and Energy level (b1300).

Table 4.2.

Frequency counts of all the responses under the domain of impairments of body functions

Function	ICF code	PQ (n=121)	LEQ (n=200)	Total (n=321)
Sleep function	b1134	0	1	1
Temperament and personality functions	b126	3	2	5
Optimism	b1265	2	2	4
Confidence	b1266	2	6	8
Energy and drive functions	b130	0	6	6
Energy level	b1300	1	15	16
Motivation	b1301	0	9	9
Energy and drive functions, unspecified	b1309	0	1	1
Sleep functions	b134	0	2	2
Amount of sleep	b1340	0	1	1
Emotional functions	b152	60	83	143
Range of emotion	b1522	22	56	78
Emotional functions, others specified	b1528	2	1	3
Thought functions	b160	0	4	4
Thought functions, other specified	b1608	2	1	3
Time management	b1642	4	1	5
Increased blood pressure	b4200	0	3	3
Problem solving	b1646	21	0	21
Hearing functions	b230	2	0	2
Pain in head and neck	b28010	0	5	5
Blood pressure	b420	0	1	1

4.3 Activity Limitations and Participation Restrictions

Activity Limitations and Participation Restrictions was the most frequently listed problem and life effects associated with parental stress, with 358 responses, including 210 responses from PQ and 148 from LEQ. The most frequently occurring category pertained to Economic life (d879), followed by recreation and leisure (d920), making decisions (d177), socialising (d9205) and Mobility (d498) as shown in Table 4.3.

Table 4.3.

Frequency counts of all the responses under the domain of Activity Limitation and Participation Restrictions

Function	ICF code	PQ (n=210)	LEQ (n=148)	Total (n=358)
Solving problems	d175	12	7	19
Making decisions	d177	32	3	35
Undertaking a single task	d210	1	0	1
Undertaking multiple tasks	d220	6	3	9
Undertaking multiple tasks, unspecified	d2209	2	0	1
Carrying out daily routine	d230	1	5	6
Completing the daily routine	d2302	0	1	1
Handling responsibilities	d2400	3	5	8
Handling stress	d2401	2	5	7

Handling crisis	d2402	0	1	1
Communicating with - receiving - spoken messages	d310	2	0	2
Communicating with - receiving - nonverbal messages	d315	3	0	3
Communicating with - receiving - formal sign language messages	d320	2	0	2
Communicating - receiving, other specified and unspecified	d329	1	0	1
Communication - producing, other specified and unspecified	d349	1	0	1
Conversation	d350	5	0	5
Using communication devices and techniques	d360	3	1	4
Moving around, unspecified	d4559	1	0	1
Moving around in different locations	d460	1	0	1
Using transportation	d470	1	0	1
Handling stress and other psychological demands	d240	3	0	3
Handling stress and other psychological demands, other specified	d2408	0	2	2
Mobility, other specified	d498	30	1	31
Mobility, unspecified	d499	1	0	1
Looking after one's health	d570	0	1	1
Self-care, other specified	d598	0	1	1
Self-care, unspecified	d599	0	5	5
Renting a place to live	d6101	3	0	3
Preparing meals, unspecified	d6309	0	1	1

Doing housework	d640	0	6	6
Maintaining assistive devices	d6504	6	0	6
Assisting others in communication	d6602	4	2	6
Assisting others, other specified	d6608	2	0	2
Basic interpersonal interactions	d710	1	0	1
Family relationships	d760	1	1	2
Parent-child relationships	d7600	15	14	29
Family relationships, unspecified	d7609	0	1	1
School education	d820	3	2	5
Acquiring, keeping and terminating a job	d845	1	1	2
Seeking employment	d8450	0	1	1
Maintaining a job	d8451	2	3	5
Terminating a job	d8452	2	6	8
Acquiring, keeping and terminating a job, unspecified	d8459	2	0	2
Remunerative employment	d850	4	0	4
Economic life, other specified and unspecified	d879	37	7	44
Community life	d910	1	0	1
Informal associations	d9100	1	0	1
Recreation and leisure	d920	2	35	37
Hobbies	d9204	0	1	1

Socializing	d9205	8	25	33
Recreation and leisure, unspecified	d9209	0	1	1
Community, social and civic life, other specified	d998	1	0	1
Community, social and civic life, unspecified	d999	1	0	1

4.4 Environmental factors and personal factors

This was the least mentioned category with 103 responses, including 72 from PQ and 31 from LEQ. The most frequently occurring categories included “Individual attitudes of extended family members” (e415), "Support and relationships of Immediate family” (e310), “Social attitudes” (e460), and Health professionals (e355) shown in (Table 5). Personal factors with an overall count of 67 responses in PQ and 31 in LEQ) were reported. The most frequently occurring categories are given in Table 6. Only 13/862 keywords in responses were not coded by the reviewers as they were deemed not belonging to any ICF codes given in table 4.4 and 4.5.

Table 4.4.*Frequency counts of all the responses under the domain of environmental factors*

Function	ICF code	PQ (n=72)	LEQ (n=31)	Total (n=103)
Support and relationships, Immediate family	e310	8	12	20
Health professionals	e355	8	1	9
Support and relationships, other specified	e398	2	2	4
Support and relationships, Extended family	e315	3	1	4
Individual attitudes of immediate family members	e410	5	0	5
Individual attitudes of extended family members	e415	18	5	23
Individual attitudes of friends	e420	1	1	2
Individual attitudes of acquaintances, peers colleagues, neighbours and community members	e425	2	1	3
Individual attitudes of stranger	e445	0	2	2
Societal attitudes	e460	16	3	19
Attitudes, other specified	e498	2	3	5
Health services, systems and policies	e580	1	0	1

Table 4.5

Frequency counts of all the responses under the domain of personality factors

Function	PQ (n=34)	LEQ (n=46)	Total (n=80)
Personal factor	22	45	67
Non codable	12	1	13

4.5 Caregiver Strain Questionnaire responses

The ratings of 100 participants were recorded and analysed. The question rated “Very much” by most of the participants was “How sad or unhappy did you feel as a result of your child’s hearing impairment?”, “How worried did you feel about your child’s future?”, “In general, how much of a toll has your child’s hearing impairment taken on your family?”. The question most rated “Not at all” was “Your child getting into trouble with the neighbours, the school, the community, or law enforcement?” (Table 4.6).

Table 4.6*Frequency of responses in CGSQ items*

Sl. No.	CGSQ Questions	Frequency count for each rating				
		1	2	3	4	5
1.	Interruption of personal time resulting from your child's hearing impairment?	29	19	19	25	5
2.	You missing work or neglecting other duties because of your child's hearing impairment?	41	20	17	15	7
3.	Disruption of family routines due to your child's hearing impairment?	52	23	16	4	5
4.	Any family member having to do without things because of your child's hearing impairment?	55	13	20	10	2
5.	Any family member suffering negative mental or physical health effects as a result of your child's hearing impairments?	38	12	18	23	9
6.	Your child getting into trouble with the neighbours, the school, the community, or law enforcement?	74	10	5	9	2
7.	Financial strain for your family as a result of your child's hearing impairment?	37	10	10	25	18
8.	Less attention paid to other family members because of your child's hearing impairment?	67	7	7	12	7
9.	Disruption or upset of relationships within the family due to your child's hearing impairment?	66	9	9	11	5
10.	Disruption of your family's social activities resulting from your child's hearing impairment?	56	14	10	13	7
11.	How isolated did you feel as a result of your child's hearing impairment?	51	1	3	18	17
12.	How sad or unhappy did you feel as a result of your child's hearing impairment?	2	7	2	33	56
13.	How embarrassed did you feel about your child's hearing impairment?	75	10	3	4	8
14.	How well did you relate to your child?	6	4	39	33	18
15.	How angry did you feel toward your child?	77	10	3	6	4
16.	How worried did you feel about your child's future?	3	8	4	41	44
17.	How worried did you feel about your family's future?	69	10	8	2	11
18.	How guilty did you feel about your child's hearing impairment?	70	10	4	4	12
19.	How resentful did you feel toward your child?	68	13	8	3	8
20.	How tired or strained did you feel as a result of your child's hearing impairment?	53	19	15	12	1
21.	In general, how much of a toll has your child's hearing impairment taken on your family?	8	12	7	37	36

4.5 Correlation between ICF codes and CGSQ.

Spearman's rank correlation for ICF codes and CGSQ response revealed that there was no significant relationship ($p < 0.05$) between different domains of ICF and CGSQ domains (Table 4.6). Activity limitation and participant restriction and environmental factors in life effect question shows a significant relationship with CGSQ domains, as shown in Table 7.

Table 4.7.

Correlation between ICF domains and CGSQ

ICF domains	Spearman's rho Correlation			Significance (p)		
	CGSQ	CGSQ	CGSQ	CGSQ	CGSQ	CGSQ
	Family	Self	overall	Family	Self	overall
BF PQ	0.11	0.21	0.17	0.27	0.03	0.08
AL PQ	0.13	-0.77	0.02	0.17	0.44	0.78
EF PQ	0.20	0.06	0.14	0.78	0.44	0.17
PFPQ	0.06	0.17	0.12	0.54	0.08	0.22
Overall PQ	0.28	0.11	0.21	0.00	0.26	0.03
BF LEQ	0.03	-0.13	-0.07	0.30	0.27	0.34
AL LEQ	0.30	0.27	0.34	0.00	0.00	< 0.00
EF LEQ	0.50	0.96	0.81	-0.06	0.00	0.02
PF LEQ	0.02	-0.09	-0.04	0.77	0.34	0.65
Overall LEQ	0.14	-0.00	0.08	0.15	0.99	0.40

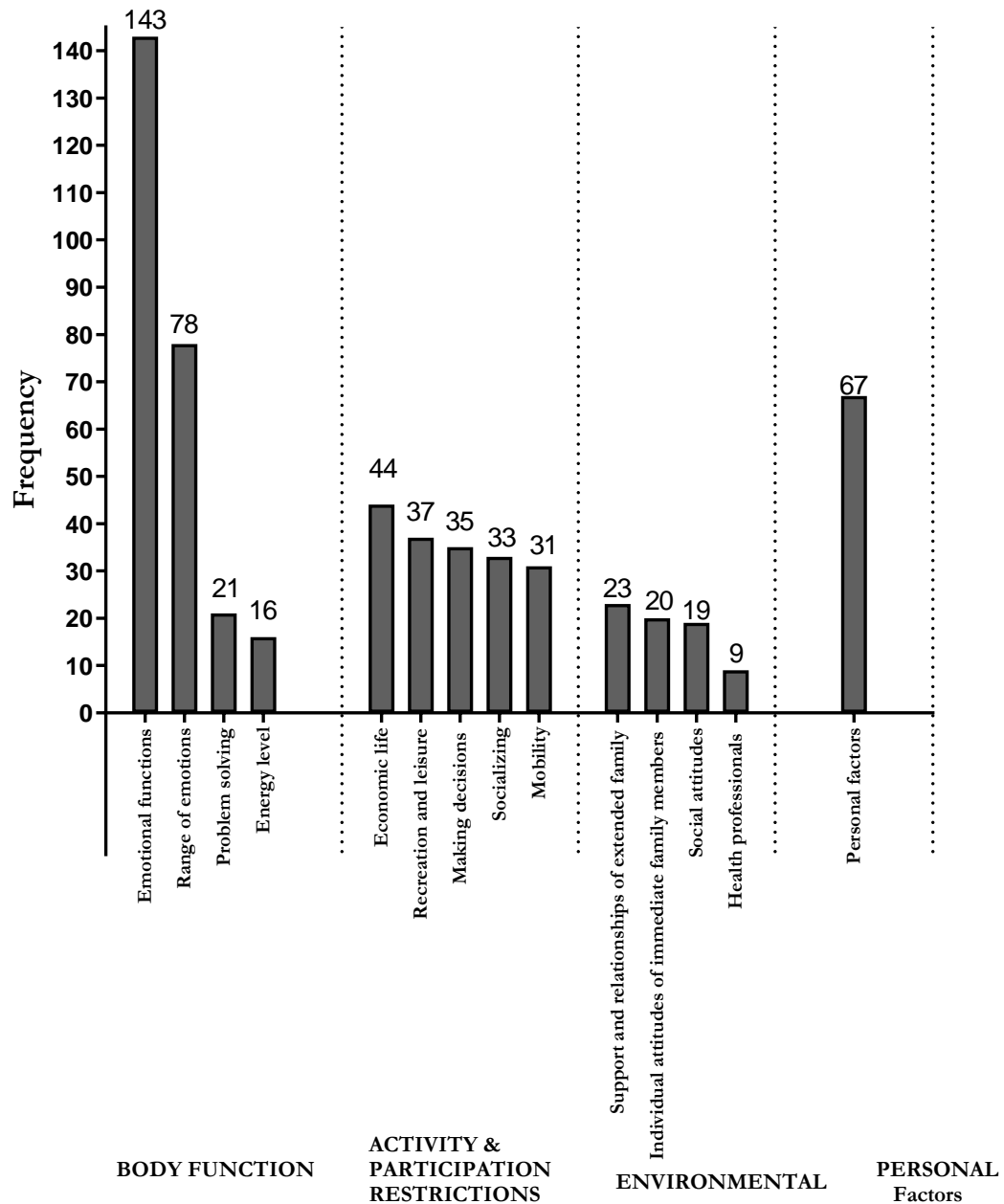
In summary, Bland-Altman analysis revealed high inter-coder reliability. 437 responses were related to problems faced and 425 responses were related life effects. Thirteen responses did not fit into any of the ICF categories. The Wilcoxon signed rank test revealed that participants experienced more difficulties in PQ than LEQ. Most of the responses were related to activity limitations, and participation restrictions, followed by body function, highlighting the stress induced limitations in their day-to-day activities from a psychosocial perspective. Spearman correlation of ICF codes and CGSQ domain revealed no significant relationship between the two variables.

Chapter V

DISCUSSION

The present study investigated the problems and life effects experienced by 100 mothers of children with hearing impairment (HI) using an open-ended questioning approach. Responses from each participant were coded using the International classification of functioning, disability and health (ICF) system. There were in total of 862 meaningful responses (PQ: 437 responses, and LEQ: 425 responses) from the participants, with 2-6 meaningful responses (Figure 2) from each, reflective of a greater degree of difficulties faced by the mothers of children with HI. The responses coded on the ICF belonged to various categories such as body functions (321/862, Table 4.2), Activity limitation and participation restriction (358/862, Table 4.3), environmental factors (103/862, Table 4.4), personal factors (67/862, Table 4.5) show the multi-faceted nature of stress in parents of HI children and its impact on various domains. Also, it points out that including an open-ended questioning approach has a significant effect in generating the appropriate responses. The ICF domains were not showing correlation with the caregiver Strain Questionnaire responses, denoting that all the problems that can be elicited and coded in ICF based analyses were not readily apparent in the closed CGSQ responses. This signifies that a more comprehensive understanding of parental stress in children with hearing HI is essential beyond a close ended questionnaire.

Figure 5.1. The bar graph depicting the most frequently reported factors due to parental stress for all domains (body function, activity limitation and participation restrictions, environmental factors, and personal factors).



5.1 Functioning and disability

Body function restrictions were impacted second most frequently (321/862, Table 4.2). Emotional function (b152) was the domain with the highest responses overall at 143 responses and range of emotion (b1522) with 78 responses (Figure 5.1). The finding that emotional function was the highest frequency in body function can be attributed to the countless emotions a parent might feel after receiving their child's diagnosis of HI. After receiving the diagnosis, they may experience an extensive range of emotions involving initial shock followed by other various emotions such as disbelief, denial, avoidance, grief, worry, and fear (Koester & Meadow-Orlans, 1990 d). Mothers of children with hearing disability may struggle with shame, self-blame, resentment, somatic complaints, depression, withdrawal symptoms, marital problems, child abuse, and/or over perceived failures (Lenhard et al., 2005). According to studies examining hearing parent-child dyads, higher parental stress was linked to increased parental depression (Gelfand et al., 1992). Ellis (1989) stated that parents of children with HI may also suffer self-doubt, embarrassment, disappointment, a sense of helplessness, remorse, panic, and feel overwhelmed. Additionally, parents of children with disabilities may experience anger due to unfulfilled expectations (Luterman, 2008 c). Many parents of school-aged children with hearing loss also express anxiety for their children's scholastic performance and future (Kurtzer-White & Luterman, 2003 c).

Problem-solving (b1646) have 21 responses accounting to be the next frequently affected domain in body function (Figure 5.1). Coping behaviour necessitates the use of many skills, one being the problem-solving skills (Folkman, 1979). Parents of children with HI deal with continuous practical difficulties such as handling hearing aids and/or cochlear implants, scheduling more expert medical and

audiological examinations, and dealing with other professional appointments. Initially, it may be a challenge for the parent to handle several appointments (Zaidman-Zait et al., 2015), problems with handling the given information (Isarin et al., 2015) and result of poor coordination between the various professionals (Isarin et al., 2015). Also, the severity of the hassles associated with parenting on a daily basis might make mothers feel more stressed. These difficulties may include challenges with handling parental responsibilities like setting up childcare and bedtime routines, as well as frustration that may arise from interactions with the child (Pipp-Siegel et al., 2002).

Energy level” (b1300) domain was observed to have 16 responses (Figure 5.1). Few participants have reported that they feel a sense of fatigue, headache and vertigo. Mothers who sacrifice their own needs and desires for the benefit of their children frequently experience maternal burnout (MB), which is characterised by feelings of exhaustion, guilt, humiliation, and resentment. Its physical symptoms included lowered immunological responses, irregular eating patterns, sleeplessness, and elevated blood pressure or heart rate (Reuben, 2013). Mothers of hearing-impaired children are particularly impacted, with detrimental effects seen in almost every domain of health (Aras et al., 2014).

When compared to other domains in ICF, activity limitation and participant restrictions was the most frequently affected domain (358/862, Table 4.3). “Economic life” (d879) is the most frequently affected domain in the activity limitation and participation restriction with 44 responses (Figure 4.3). This finding is in support with numerous reports which show that expenses on HI child can place a significant social and financial hardship on families (Pipp-Siegel, 2002; Puff & Renk, 2014; Quittner et al., 1990; Yucel et al., 2008). According to Yucel et al (2008), poor socio-economic situation of the family is one of the main variables that may prolong the time between

amplification and intervention, with the families experiencing financial constraints in hearing aid purchase. Pipp-Siegel et al(2002) in his study concluded that mothers with lower incomes reported feeling more stressed. Similar effects of poor income negatively impacting parental stress were discovered by (Quittner et al., 1990).

Recreation and leisure (d920) is the next most reported (Figure 5.1). According to research, family, caregivers, particularly those who look after children with disabilities, frequently experience limited leisure time due to a number of special constraints, such as a caregiving moral support (Henderson & Allen, 2013), stress and health issues (Marks, 1996), lack of time and energy from caregiving responsibilities (King et al., 2000), a lack of knowledge (Buettner & Langrish, 2020), and social isolation (Valtchanov et al., 2017). In addition to the above, making decisions (d177) domain has 22 responses. Parents are provided with technical information and the need to make choices regarding a wide variety of alternatives at the time of identification or shortly after, including communication options, early intervention, and sensory equipment (Fitzpatrick et al., 2008).

Making decisions may be difficult, stressful, and emotionally taxing for parent . As a result of the absence of early guidance, mothers have also stated that they must visit many professionals to come to a decision. Few parents struggled to interpret medical information, while other parents feel that the information offered concerning hearing aids is insufficient (Eyalati et al., 2013). Parents of children with HL stated a desire and clear information as one of their key demands (Schmulian & Lind, 2020). Hence, audiologists, doctors, or other professionals must frequently provide additional information and assistance to parents of HI children.

In addition to the above Socializing (d9205) with 33 responses followed by mobility (d498) with 31 responses were also reported to be the other domains affected in the activity limitations and participation category. As per (Lederberg & Golbach, 2002) having a child with HI may have a variety of effects on mother's social networks. Mothers of HI children reported to have smaller social networks (Quittner et al., 1990). They also mentioned that they may not have the time necessary to build and maintain social networks, hence affecting their size. Also, parents reported having less time for themselves.

5.2 Contextual Factors

These are the least mentioned domains (183/862 Table 5&6) in the present study. "Support and relationships of extended family members" (e415) is the most frequently mentioned domain in the environmental factors with 20 responses. The other frequently affected domains are individual attitudes of immediate family members" (e410), "Social attitudes" (e460), "and "Health professionals" (e355).

Research reports are consistent with the finding of poor societal attitudes/stigma that mothers of HI often claim to encounter (Ebrahimi et al., 2015). A significant proportion of mothers felt ashamed as a result of the criticism, sympathies, and odd stares they received from the society (Ebrahimi et al., 2015) Mothers of HI also claimed that because of their children's condition, they had experienced discrimination, loneliness, and ostracism from family and friends. Similarly, mothers of children with HI also connected feelings of guilt and helplessness with a discouraging negative social attitude (Ebrahimi et al., 2015). Studies have discovered that societal attitude and support are crucial in moderating parent stress, and several investigations of parent stress in families with HI children have indicated a significant impact of social support

on parent well-being (Dirks et al., 2016). Consistent findings state that the competence of parents to deal with their child's deafness depends heavily on social support (Lederberg & Golbach, 2002; Meadow-Orlans, 2016 d; Oelofsen & Richardson, 2006; Pipp-Siegel et al., 2002s, Sara et al). Additionally, it has been reported that the level of support given to mothers has a substantial impact on the effectiveness of mother-child interactions (MacTurk et al., 1993) which has been linked to greater language development in preschool-aged children (Pressman, Pipp-Siegel, Yoshinaga-Itano, & Deas, 1999). Therefore, raising awareness and lowering the stigma faced by mothers of HI children may be achieved by educating the parent and the general public.

Family members undergo a continuous process rather than a finite series of emotions every now and then sequentially. Trigger events may occur in them while observing another child conversing and playing, attending birthday celebrations, during teacher conferences, and consulting audiologist are a few instances of these occasions (KurtzerWhite&Luterman, 2003). According to some researchers, the support of immediate family member especially spousal support is the biggest predictor of parental stress in all families, with parents in unhappy marriages expressing the most anxiety (Deater-Deckard & Scarr, 1996). In addition, the individual attitude (or) self-perceived attitude of the mothers with HI children also is an important factor. Self-efficacy in parenting refers to parents' perceptions of their capacity to carry out their parental responsibilities with competence (Coleman & Karraker, 2003; Jones & Prinz, 2005). Ability of the mother to accept their child's impairment, cope according to it, and meet the child's needs may have a significant positive impact on the child's wellbeing and social, emotional, and language development (Calderon, 2000; DesJardin & Eisenberg, 2007; EB Cole, 2007).

They also needed professional help to deal with caring responsibilities and activities (Wong et al., 2004). Early intervention by professionals providing psychological support and helpful advice may (indirectly) reduce parental stress owing to the better language and social-emotional outcomes in children with HL (Meinzen-Derr et al., 2011; Moeller, 2000; Stika et al., 2015; Yoshinaga-Itano, 2003).

5.3 Caregiver Strain Questionnaire responses

The responses from CGSQ (Table 4.6) indicate that the responses are not equally distributed across participants. Although CGSQ can rate different domains, not all the aspects of parental stress are manifested. This implies that the CGSQ items are insufficient to adequately define the many facets of parental stress.

5.4 Correlation between ICF domains and CGSQ responses

Spearman's rank correlation for ICF codes and CGSQ response revealed that there was no significant relationship ($p < 0.05$) between different domains of ICF and CGSQ domains (Table 4.6). Activity limitation and participant restriction and environmental factors in life effect question shows a significant relationship with CGSQ domains. This indicates that most of the CGSQ questions are focused on these two domains only. Whereas, ICF questions were able to retrieve responses from various domains. Therefore, in order to identify all the domains, an ICF-based questionnaire that covers more extensive elements of parental stress is essential (Appendix II).

5.5 Study implications

Based on the findings from the present study, it is evident that close ended Caregiver Strain Questionnaire is not correlating with the ICF domains, indicating that it assesses only fewer aspects of parental stress. The biopsychosocial approach in

assessing parental stress in parents of children with HI gives a better understanding. It is clear that the parents of children with HI are not experiencing the issues in one domain but in various domains (e.g., Body function: Emotional functions, Range of emotion, Problem-solving; Activity limitation and participation restriction- Economic life, Recreation and leisure, making decisions, socialising and Environmental Factors- Individual attitudes of extended family members, Support and relationships of Immediate family, Social attitudes). Thus, the open-ended questions were very much helpful in gathering required information with a broader range of health and stress issues in parents of HI children. Based on these findings, a structured questionnaire covering all the domains was developed based on ICF core sets to help professionals dealing with parents of children with HI to verify the stress related aspects in them, as shown in Appendix II.

Further, the professionals serving the parents of these children should be aware of the importance of family centered (Bronfenbrenner, 1970) intervention. The intervention will be effective if the professionals are able to identify domain-specific impact in them, providing comprehensive awareness of various stressors and their perception of their child's hearing impairment. Apart from providing an overall understanding of the parent's perception of the impairment, the professionals can use these bio-psychosocial indicators to provide appropriate support to them over time. Early intervention must take into account the unique stressors associated with having a child with HI in order for parents to restore the energy, drive, and emotional availability essential for a pleasant and productive parent-child connection. Furthermore, given the importance of parent-child interaction in the development of a child with HI, early intervention should provide direct parent assistance for optimum communication and language to their child's requirements (Holzinger et al., 2022). Also, the government

can expand the current support services pertinent to the welfare of parents of children with HI and entitle them with more concessions. Therefore, offering family based interventions can be a crucial part of assisting family members, especially mothers, to better understand disabilities, provide services, and learn how to manage stress in daily life, all of which will enhance their mental health and which will have an impact on the development of the HI child.

5.6 Strengths and limitations of the Study

The study used open-ended questions, which have the advantage of covering broader aspects than structured questions (Manchaiah et al., 2018; Stephens & Pyykkö, 2011). The number of responses to each question was high in this study. The ICF codes are more reliable since we included three coders.

The ICF categories in this study was not correlated between different hearing devices (Hearing aid, CI or bimodal), age of identification, socioeconomic factors, education of mothers, different auditory tests (degree, type, speech identification scores, aided benefit and evoked potential responses). Future studies can address the major co-variants/factors that could be attributed to parental stress. Also, the participants in this study were only mothers of children with HI. In addition, the inclusion of both the father and mother (in contrast to only mother used in the study) can determine gender-specific stress. The ICF domains can be correlated with other close ended questionnaires to measure its impact.

Chapter VI

SUMMARY AND CONCLUSIONS

The present study investigated problems (PQ) and life effects (LEQ) experienced by 100 parents of HI children using an open-ended questioning approach. Responses from each participant were coded using the ICF classification system. There were 862 meaningful coded responses (PQ: 437 responses, and LEQ: 425 responses) from the participants. The responses from problem and life effect question were not statistically significant. Activity limitations and participation restrictions is the most frequently affected, which is followed by body functions. The environmental factors and personal factors had the least number of responses. The most frequently listed function is “Emotional functions” (b152), “Range of emotion” (b1522), “Problem-solving (b1646), “Energy level” (b1300). The most frequently occurring responses related to activity limitation and participation restriction were “Economic life” (d879), followed by “Recreation and leisure” (d920), making decisions (d177), “socialising” (d9205), “Mobility” (d498), and; Environmental factors- “Individual attitudes of extended family members” (e415), “Support and relationships of Immediate family” (e310), “Social attitudes” (e460). Personal factors involved individual character style. These responses accentuate the need for understanding the multi-faceted nature of parental stress and its impact on their life. Also, it points out that including an open-ended questioning approach has a significant effect in deriving broader range of issues from parents of hearing impaired instead of close ended Caregiver strain Questionnaire. The findings from the study showed that stress in parents of children with HI are mainly linked to activity limitations and participant restrictions followed by body function and environmental factors. A small number of personal factors were also coded in the

affected domains. These functions clearly show that parents of HI experience issues in many domains, which are not otherwise reflected in single close-ended questionnaires. An effective family-based intervention strategies can be established based on this ICF core set.

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APPENDIX I**Data Collection Sheet****SECTION – 1 (DEMOGRAPHIC DETAILS)**

Demographic details of **parents**:

1. Name
2. Age:
3. Education:
4. Profession
5. Family income.....
6. History of any psychological issues before diagnosis of the child.

Demographic details of **child**:

1. Name
2. Age/Gender:
3. Education:
4. Sibling history of child
5. Age of identification of hearing impairment/loss
6. Intervention device
7. Duration of device use
8. Duration of therapy

SECTION - 2**ICF BASED QUESTIONS**

1. MAKE A LIST OF THINGS YOU FIND CHALLENGING OR PROBLEMS YOU HAVE DUE TO YOUR HEARING PROBLEM. LIST AS MANY AS YOU THINK OF

- a. Do you want to answer by text?
- b. Do you want to upload image?
- c. Do you want to upload a voice recording?

2. PLEASE STATE THE EFFECTS OF HEARING PROBLEM ON YOUR DAY TO DAY LIFE. LIST ALL THE EFFECTS, AS MANY AS YOU CAN

- a. Do you want to answer by text?
- b. Do you want to upload image?
- c. Do you want to upload a voice recording?

SECTION – 3

Caregiver Strain Questionnaire

Please think back over the past 6 months and try to remember how things have been for your family. We are trying to get a picture of how life has been in your household over that time.

For each question, please tell me which response (which number) fits best.

In the past 6 months, how much of a problem was the following:

	Not at all	A little	Some what	Quite a bit	Very much
1. Interruption of personal time resulting from your child's hearing impairment?	1	2	3	4	5
2. You missing work or neglecting other duties because of your child's hearing impairment?	1	2	3	4	5
3. Disruption of family routines due to your child's hearing impairment?	1	2	3	4	5
4. Any family member having to do without things because of your child's hearing impairment?	1	2	3	4	5
5. Any family member suffering negative mental or physical health effects as a result of your child's hearing impairment?	1	2	3	4	5

- | | | | | | | |
|-----|--|---|---|---|---|---|
| 6. | Your child getting into trouble with the neighbors, the school, the community, or law enforcement? | 1 | 2 | 3 | 4 | 5 |
| 7. | Financial strain for your family as a result of your child's hearing impairment? | 1 | 2 | 3 | 4 | 5 |
| 8. | Less attention paid to other family members because of your child's hearing impairment? | 1 | 2 | 3 | 4 | 5 |
| 9. | Disruption or upset of relationships within the family due to your child's hearing impairment? | 1 | 2 | 3 | 4 | 5 |
| 10. | Disruption of your family's social activities resulting from your child's hearing impairment? | 1 | 2 | 3 | 4 | 5 |

In this section, please continue to look back and try to remember how you have felt during the past 6 months.

For each question, please tell me which response (which number) fits best.

In the past 6 months:

	Not at all	A little	Some what	Quite a bit	Very much
11. How isolated did you feel as a result of your child's hearing problem?	1	2	3	4	5
12. How sad or unhappy did you feel as a result of your child's hearing impairment?	1	2	3	4	5
13. How embarrassed did you feel about your child's hearing impairment?	1	2	3	4	5
14. How well did you relate to your child?	1	2	3	4	5
15. How angry did you feel toward your child?	1	2	3	4	5
16. How worried did you feel about your child's future?	1	2	3	4	5
17. How worried did you feel about your family's future?	1	2	3	4	5

- | | | | | | | |
|-----|--|---|---|---|---|---|
| 18. | How guilty did you feel about your child's hearing impairment? | 1 | 2 | 3 | 4 | 5 |
| 19. | How resentful did you feel toward your child? | 1 | 2 | 3 | 4 | 5 |
| 20. | How tired or strained did you feel as a result of your child's hearing impairment? | 1 | 2 | 3 | 4 | 5 |
| 21. | In general, how much of a toll has your child's hearing impairment taken on your family? | 1 | 2 | 3 | 4 | 5 |

APPENDIX II

**QUESTIONNAIRE ON QUALITY OF LIFE IN PARENTS OF CHILDREN
WITH HI**

S. NO	Questions	Severity				
Body Function						
1.	How often do you feel these range of emotions?					
a)	Sad/Depressed	1	2	3	4	5
b)	- Fear/Tension/Anxiety	1	2	3	4	5
c)	- Guilt/Helplessness	1	2	3	4	5
2.	How often are you able to solve problems related to child's hearing impairment?	1	2	3	4	5
3.	How much are you aware of hearing loss?	1	2	3	4	5
4.	Do you experience tiredness/fatigue due to your child's hearing impairment?	1	2	3	4	5
5.	Do you find yourself demotivated to deal with your child's hearing impairment?	1	2	3	4	5
6.	How confident are you in dealing with your child's hearing impairment?	1	2	3	4	5

Activity Limitations and participant restriction

- | | | | | | |
|---|---|-----|---|----|---|
| 7. Do you feel restricted from participating in any form of recreation/leisure activity due to your child's HI? | 1 | 2 | 3 | 4 | 5 |
| 8. Do you face financial hardship due to your child's HI? | 1 | 2 | 3 | 4 | 5 |
| 9. How often can you make an effective choice among options for your hearing impaired child? | 1 | 2 | 3 | 4 | 5 |
| 10. Is your social life affected due to your child's hearing impairment? | 1 | 2 | 3 | 4 | 5 |
| 11. Have you had to relocate to a different place for better treatment for your child? | | YES | | NO | |
| 12. If yes, then how inconvenient was it for you? | 1 | 2 | 3 | 4 | 5 |
-

Environmental factors

13. Has your child's HI affected your relationship with:
- a) - Immediate family members 1 2 3 4 5
- b) - Extended family members 1 2 3 4 5
14. Has the individual attitude of family members led to
- a) - Lack of support 1 2 3 4 5
- b) - Or their difference in opinions 1 2 3 4 5
- hindered your ability to provide appropriate rehabilitation for your child?
- 15 Has the social stigma/Prejudices/Myths surrounding HI affected you as a parent 1 2 3 4 5
- 16 Are you satisfied with the services/support provided by the health professionals? 1 2 3 4 5

Personal factors

- 17 Are you able to cope with the fact that your child is hearing impaired? 1 2 3 4 5
- 18 How concerned are you about your child's future? 1 2 3 4 5
-