Adaptation and Validation of Paediatric Hearing Impaired Caregiver's Experience (PHICE) Questionnaire in Kannada

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CERTIFICATE

This is to certify that this dissertation entitled '**Adaptation and Validation of Paediatric Hearing Impaired Caregiver's Experience (PHICE) Questionnaire in Kannada'** is a bonafide work submitted in part fulfilment for degree of Master of Science (Audiology) of the student Registration Number: 17AUD023. 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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CERTIFICATE

This is to certify that this dissertation entitled '**Adaptation and Validation of Paediatric Hearing Impaired Caregiver's Experience (PHICE) Questionnaire in Kannada'** has been prepared under our supervision and guidance. It is also been certified that this dissertation has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled **‘Adaptation and Validation of Paediatric Hearing Impaired Caregiver’s Experience (PHICE) Questionnaire in Kannada’** is the result of my own study under the guidance a faculty at 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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May, 2019

Dedicated to our friend Late. Wantei

For his humbleness, love towards football and good human being

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Chapter 1

Introduction

Hearing impairment is defined as a condition that can have both complete and partial loss ofability of an individual to hear. Hearing loss is found to be the most common disability in newborns, having a significant impact on the child and his/her family. It is reported in India that around 63 million people (6.3%) suffer from significant hearing loss (World Health organization, 2012). Also the estimation report indicated that four in every 1000 children suffer from severe to profound hearing loss. It has also been reported that more than 90% of deaf children are born to normal hearing parents (Chaudhury, 2014).

The community demand on children with hearing loss is huge with respect to education, socialization, financial independence and communication and hence invariably the push is evident for early identification of children with hearing loss (Calderon, 2000; Yoshinaga-Itano, Sedey, Coulter, &Mehl, 1998). Hence, the Universal New born Hearing Screening (UNHS) rigorously initiated to screen newborn's children's hearing status. Early identification of hearing loss is found to have a significant impact on a child's overall development (Downs &Yoshinaga-Itano, 1999; Mauk, White, Mortensen, & Behrens, 1991; Mencher, 1976). Specifically birth to five years of age is considered as critical period for language development. The pre-linguistic hearingloss is noted to have a greater impact on acquisition ability to extract communication cues from the environment (Ramkalawan& Davis, 1992). It is also been noted that the identification of hearing loss during early years altered the family adjustment (Kurtzer-White &Luterman, 2003; ASHA, 2008). The common reactions like denial, shock, grief, abandonment, social exclusion are frequently reportedin parents of children with disability (Luterman, 1979;

Luterman& Ross, 1991). Accordingly the coping process of the family members changes the view about the child (Kurtzer-White &Luterman, 2003). Parents are usually left alone in managing a child hearing impairment during early life of the child without any emotional preparation. And hence stress followed by the diagnosis often creates anticipatory anxiety (Young & Tattersall, 2007, Feher-Prout, 1996) which invariably impairs the decision making process(Miu, Heilman, & Houser, 2008).

It remains important for educators and interventionist to be aware of the repercussions of parental stress, not only during the child's infancy, but also throughout the rehabilitation process (Koester & Meadow-Orlans, 1990). Addressing parental stress and emotions early in the process of diagnosis provides support in making decisions leading to better compliance to the therapeutic process.Another critical component of the child's psycho-social development is found to be the parent-child relationship (Hintermair, 2006; Koester & Meadow-Orlans, 1999; Zaidman-Zait& Most, 2005). The long-term impact on the family pave the way to be emotional vulnerable, experiencing depression, feelings of disgrace, denial and the need to change their lives in order to meet the ongoing challenges (Anagnostou, Graham, & Crocker, 2007; Calderon & Greenberg, 1999; Feher-Prout, 1996; Hintermair, 2006; Kurtzer-White &Luterman, 2003; Kushalnagar, Krull, Hannay, Mehta, Caudle, &Oghalai, 2007; Lederberg&Golbach, 2002; Zaidman-Zait, 2007). Various questionnaires have been used to assess the stress related issues in caregiver's of children with hearing impairment. A tool such as Paediatric Hearing Impairment Caregiver's Experience (PHICE) has been used to assess the stress related factors of caregiver's of hearing impaired children(Meinzen-Derr, Lim, Choo, Buyniski, & Wiley, 2008).

Meinzen-Derr et al., (2008)developed and validated a PHICE questionnaire examining various stressors that the families experience after the diagnosis of child's hearing loss. The PHICE was created using an “expert panel” consisting of professionals caring for children who were deaf/hard of hearing (hoh) and caregivers of children who were deaf/hard of hearing. The expert panel consisted of 11-member team that included specialist doctors from the Departments of Developmental and Behavioural Pediatrics, Psychology, Paediatric Otolaryngology, a medical social worker, a speech rehabilitation therapist, an aural rehabilitation therapist, an audiologist, and program/education directors/principals of the state's early intervention system and schools for the deaf (both oral & signing).

The PHICE is a 68-item questionnaire which covers 8 domains of stress. These domains include: communication (10 questions), education (7 questions), emotional well-being (11 questions), equipment (3 questions), financial (4 questions), healthcare (14 questions), social (8 questions), and support (11 questions). Parents are required to rate stress on an 8-point Likert scale that range from no stress to extremely high stress. Lim et al (2008) reported that the PHICE was found to have an overall reliability of 0.96, which is considered to be an extremely high coefficient.Identifying and understanding stress that burden the parents and caregiver’s of hearing impaired children, it may be difficult to provide the appropriate services and interventions necessary to strengthen the parent-child relationship which is important to child’s developmental status (Lim, 2008).

A tool such as The Parenting Stress Index (PSI) has been used for measuring stress (Abidin, 1995). Pipp-Siegel, Sedey, &Yoshinaga-Itano(2002) suggested that stress levels among mothers of children who are deaf or hard of hearing are not clinically higher according to the Parental Stress Index (PSI) than a normative sample of mothers of hearing children. Parenting Stress Index (PSI) is also a widely accepted tool to measure a stress among the parents but this tool do not have a specific questions which are related to caregiver’s experiences having a child with hearing loss. The focus of present study is to modify, adapt and validate PHICE questionnaire to increase its relevance and use in India for Kannada speaking population. There is no established instrument of any such measure in Indian context in Kannada language which would address stress related factors. Hence, there is a need to validate a PHICE questionnaire which will address stress related issues in parents of hearing impaired children. The chosen questionnaire is currently validated in United States and Singapore. However, it is essential to adapt and validate in Indian context due to differing demographics.

1.1 Need for the study

1. A tool such as the Parenting Stress Index (PSI) has widely accepted to measure the stress but these tools are not sensitive enough to measure how the caregiver feels being the caretaker of a child who is being diagnosed as the hearing impairment (Meinzen-Derr, Lim, Choo, Buyniski, & Wiley, 2008). The current study has utilized a new tool which has been developed and validated to measure the stress among the caregiver' of hearing impaired children.
2. Bi-directional interaction between culture and healthcare system are unavoidable. Hence, it is essential to establish culturally relevant measure of parental stress index.
3. Rapidly changing demographics with high cultural and language loaded community like India requires ecologically valid testing methodology to understand the dynamics underlying parental stress of children with Hearing Impairment.

1.2 Aim

The aim of the study is to adapt and validate the PHICE questionnaire.

1.3 Objectives

1. To explore the emotional experiences of caregiver's of hearing impaired children.
2. To validate the PHICE questionnaire to increase its relevance and use in Indian context

Chapter 2

Review of literature

Stress is defined as ‘environmental demands tax or exceed the adaptive capacity of an organism resulting in psychological or biological changes that may place persons at risk for disease (Appley& Trumbull, 1967; Mason, 1975; McGrath, 1970). Stress is presumed to result in negative emotional state and referred as a general process where environmental demands result in outcome deleterious to health. Stress is a ‘specific external and/or internal demands that are appraised as taking or exceeding the resource of a person. A stressor is any stimulus that makes demands upon organism regarding adaptation or adjustment (Hintermair, 2004).

The caregiver’s of hearing impaired children undergo lot of stress from the time of diagnosis. Eighty percentages of children with hearing impairment are born to hearing parents (Jamieson, 2017). Many hearing parents including those of children who are deaf or hard of hearing exhibit high level of stress, which can influence the parent, child and the parent-child interaction (Lederberg &Golbach, 2002; Quittner, Glueckauf, & Jackson, 1990). Lederberg &Golbach (2002) suggested that children with hearing loss who have parents of normal hearing feel more stress than parents of hearing children and on the other hand, other studies reported no difference in stress level between the two group of parents (Meadows-Orlans, 1994; Pipp-Siegel, 2002).

In fact, the studies on stress among parents of children with hearing loss focused mainly on the areas of demographic characteristics, the degree of child’s hearing loss, as well as characteristics and perceptions of the parents. The child’s hearing loss, including age of identification and degree of loss, can have an effect on a hearing parent’s stress level (Konstantreas&Lampropoulou, 1995). In addition, other factors like the presence of additional disabilities, and factors related to the child's parents such as family income, parenting hassles, and support can also lead to greater impact on parental stress levels (Pipp-Siegel et al., 2002).

It is clearly evident from the literature that family attitude is a critical variable that determine the prognosis. Family stressors associated with limited financial resources, lack of appropriate services, and insufficient support systems are the best examples of the poor family system which serves as risk factors for poor prognosis (Gupta &Singhal, 2004). Environmental risk factors such as lack of services and negative attitudes from society can also have an impact on the compliance. It is also considered sensitive for the professionals to be competent to address the micro issues. Parents provide long-term care that often requires extraordinary physical, emotional, social and financial resources. In addition to being responsible for the physical care of their child, they must co-ordinate their child's numerous and multifaceted medical, education and developmental needs while balancing competing family needs (Silver et al., 1998). Table 2.1 provides list of studies done to assess the stress experienced by caregiver's of hearing impaired children using different tools and their results. Most of the studies report that parents of hearing impaired children experience higher level of stress compared to parents of normal hearing children and also have poorer psychological adjustment.

Table 2.1

List of studies that assessed stress in caregiver's of children with hearing impaired using various questionnaires and results.

Reference	Sample	Measuring device/test used	Results
Quittner, Steck&Rouiller, 1991.	24 mothers of children implanted with Cochlear Implant (CI).	Questionnaire assessing stressors related to parenting task, time demands and childhood deafness.	Experience higher level of stress and poorer psychological adjustment than parents of normal hearing children.
Quittner et al,1990.	96 mothers of deaf children 118 matched controls	1.Parenting Stress Index(PSI) 2.Eyberg child behavior inventory(ECBI) 3.Family stress scale(FSS) and 4.Parenting routine inventory – stress scale (PRI-SC)	Chronic parenting stress is associated with lowered perception of emotional support and greater symptoms of depression and anxiety.
Brand &Coetzer,1994.	30 hearing couples of hearing impaired children	Questionnaire on Resources and Stress(QRS)	Mothers have higher stress on perception of difficulties, less emotional support from their spouse and less free time for themselves.
Konstantreas&Lampropoulou, 1995	42 hearing mothers of deaf children	1.Rotter's locus of control scale 2.Co-opersmith's self esteem inventory 3.Clarke questionnaire on resources and stress	Mothers of young children and low esteem were associated with more stress.
Pipp-Siegel et al, 2002	184 hearing mothers of deaf children	Parenting Stress Index(PSI)	Less parental distress on PSI

Lederberg &Golbach, 2002	23 hearing mothers of deaf children and normal hearing children	Parenting Stress Index(PSI)	Mothers of deaf children feel stress specific to deafness
Hintermair, 2004	235 mothers of hearing impaired children	Sense of Coherence(SOC) Questionnaire	Sense of coherence and social support reduces stress
Burger, Spahn, Eissele&Bengel, 2005	116 fathers and mothers of Hearing impaired children	1.Symptom checklist (SCL-90-R) 2.Global Severity Index(GSI) 3.Everyday Life Questionnaire (EDLQ)	Parents experience heightened psychic stress and poor quality of life after the diagnosis and during pre-implant period
Hintermair, 2006	213 mothers and 213 fathers of deaf or hard of hearing children	1.Parenting stress index(PSI) 2.Strength and difficulties questionnaire(SDQ-D) 3.Sense of coherence(SOC) 4.Social Support questionnaire	High parental stress is associated with socio-emotional problems in children Parental access to personnel and social resources associated with lower stress experience
Meinzen-Derr et al, 2008	152 caregivers of hearing impaired children	Pediatric hearing impaired caregiver's experience (PHICE)	Parental stressors change over time with respect to time of diagnosis.
Dirks &Rieffe, 2016	Parents of 30 toddlers with moderate hearing loss and 30 hearing children	Nijmegen Parenting Stress Index (NPSI)	Parents of toddlers with moderate hearing loss was comparable to parents of hearing children

It is also said that caregiver health is related to child behavior and care-giving demands, the determinants of caregiver health and well-being are areas of much-needed investigation (Raina et al. 2005). Greater knowledge of caregiver health-related needs would allow for the improvement of existing services and the development of new strategies to sustain caregivers in their vital roles. It has been found that caregivers of hearing impaired children experience grief. The Kubler-Ross in 1969 described the five different stages of grief being experienced by individuals. The five stages are denial, anger, bargaining, depression and acceptance. The caregivers of the hearing impaired children could be in any one of these stages. No much work has been done to see the emotional reactions of these caregivers experiencing different kinds of emotional reactions. The caregiver's may experience grief due to unavailability of information and communication regarding hearing impairment, lack of emotional support, guidance and direction by professionals.

Chapter 3

Methods

The present study was taken up to adapt and validate the Pediatric Hearing Impairment Caregiver's Questionnaire (PHICE). PHICE was adapted to Kannada and information was elicited from Kannada speaking individuals who were caregiver's of hearing impaired children.The study was divided into two phases (Phase I and II). Phase I was a qualitative study done on 77 caregiver's of children with hearing impairment to understand the emotional reactions and Phase II was a quantitative study done on 100 caregiver'sof children with hearing impairment using the adapted PHICE questionnaire.

3.1 Phase I

The qualitative study was done on caregiver's of children with hearing impairment. The demographic data was collected as a part of survey. Specifically, the information related to children such as age, gender, degree of hearing loss, age of identification of hearing loss, and details of the family includes domicile, education level of parents, socio-economic status and hearing status. Informed consent was taken from the caregivers and explained about the need and aim of the study before carrying out the research.All data were obtained in compliance with the Ethical guidelines for Bio-Behavioural Research Involving Human Subjects (2009) of the All India Institute of Speech and Hearing, Mysuru. Children who were admitted in residential special school along with the caregiver were selected for the study. All the children selected were admitted in residential special school along with the caregiver.

Seventy seven participants who were caregiver's/parents of children with hearing impairment. All the children were diagnosed as permanent hearing losswith degree of hearing varying from moderate to profound. They were asked to write down the worries and doubts they have about the hearing loss in their children who are diagnosed as having permanent hearing loss.The participants were asked to write the responses in their mother tongue. Enough time was given to write their responses. Caregiver's who were not educated to read and write their language were asked to take the help of other caregiver's to help them write their worries and doubts. Professionals like the master degree students of audiology and bachelor degrees of special education students collected the responses and were present during data collection to instruct them. Written responses were collected and analyzed each of their responses later.

Responses obtained were categorized into different emotional reactions of the caregiver's being with a child with hearing impaired. Caregiver's worried about family stress, parenting discrepancies, negative reactions from the extended family member, communication difficulties and other mixed worries about their children. Few questions from the PHICE were removed which were not related to Indian context and culture.

3.2 Phase II

A total of 100 caregivers of children with permanent hearing loss who had been receiving treatment in All India Institute of speech and hearing were recruited for the study. Caregiver was defined as a parent, family member or the other personnel who takes care of the child with HI. Informed consent was taken and translated version of PHICE questionnaire was administered. All the participants were native Kannada speakers.

3.2.1 Procedure: The procedure consisted three stages: Translation, Administration of PHICE and Scoring of responses.

3.2.1.1 Translation of PHICE: The original version of PHICE which is in English language was translated to Kannada by two professionals who were experienced in the Kannada language. Later each of two sets of Kannada translated questionnaires were reverses translated by two different individuals who were proficient in both languages. In the phase of translation, items of the PHICE questionnaire that were less relevant to the Indian context were removed.

3.2.1.2 Administration of PHICE: In this stage, caregiver's of children with hearing impairment were asked to fill the questionnaire. The demographic data was collected as a part of survey. The child specific information collected were age, gender, degree of hearing loss, age of identification of hearing loss, and family oriented information like domicile, education level of parents were collected as a part of study. The adapted PHICE questionnaire is given in appendix (I-V).

3.2.1.3 Scoring of responses: Each question/item on PHICE has 8 point scale for the participant to tick. The lowest value on the 8 point Likert scale was 1 and the highest value being 8. Lowest value represents no stress and highest value represents more stress. The 8-point Likert scale on the PHICE was collapsed into a 3-point scale for the purpose of analysis. Items that represented no stress (not applicable, no stress, very low stress) were given a score of 1, items that represented some stress (low stress, moderate stress) were given 2, and items that represented high stress (high stress, very high stress) were given a score of 3. Scores were summed in each group. The lower score indicates a lower stress and higher stress indicates a higher stress with a range in a total score from 57 points (lowest possible score) to 171 points (highest possible score).

3.3 Statistical analysis

Continuous variables (age) were reported as means with standard deviation. Categorical variables (gender) were reported as proportions.The independent t-test was carried out to identify the differences between demographic characteristics with total score on the adapted PHICE. The one way ANOVA was carried out to identify the differences between levels of caregiver’s education with total score on the adapted PHICE.

Chapter 4

Results

The present study was carried out to adapt and validate the PHICE questionnaire in the Indian context for caregiver's of children with hearing impaired. The child and the subject characteristics were investigated with the PHICE score. Results are studied under two broad headings as Qualitative analysis and Quantitative analysis.

4.1 Qualitative Analysis

Seventy seven participants participated in the study. The mean age of the child with hearing loss was 4.651 years. Table 4.1 represents majority of the children were male (57.1%) as compared to females (42.9%). All the doubts and responses were filled out by mother. Most of the caregiver's were from urban area (54.5%) as compared to rural area (45.5). Most of the caregiver's education status was secondary and above (40.3) as compared to under graduation and above (33.8) and primary and below primary (26).

Table 4.1

Demographic characteristics of child and caregiver (qualitative study)

Demographics	Mean (SD)	Frequency (%)
Child Demographics		
Age (in years)	4.651(2.477)	-
Gender		
Male	-	44 (57.1)
Female	-	33 (42.9)
Caregiver Demographics		
Domicile		

Rural	-	35 (45.5)
Urban	-	42 (54.5)
Education		
Primary and below	-	20 (26)
Secondary and above	-	31 (40.3)
UG and above	-	26 (33.8)

The findings of the qualitative study are to understand the reaction patterns of caregiver's of children with hearing impaired. The emotional state of the caregiver's reflects the impact of child with hearing impaired on the family. The responses were qualitatively analyzed and coded based on the themes emerged. Themes were listed below following this procedure based on the themes questions from the original PHICE questionnaire was adapted and modified to ensure the ecological validity. The following figure represents the distribution of responses in the themes generated based on the responses of the caregiver's.

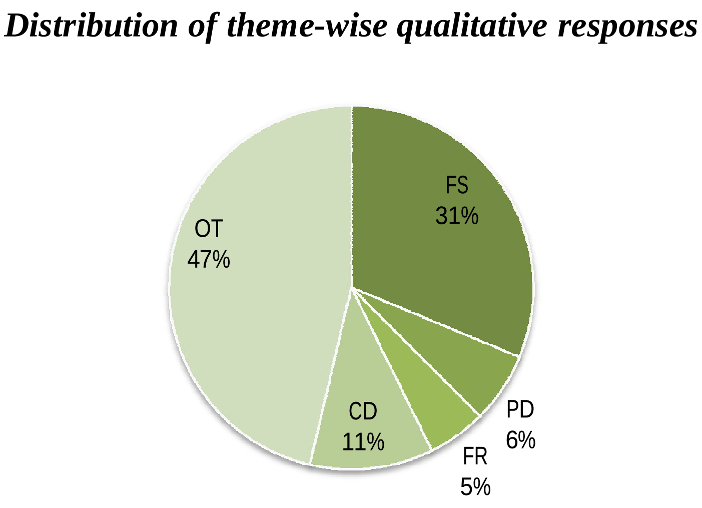

Figure4.1 Theme wise qualitative responses of caregiver's FS – Family Stress; PD – Parenting discrepancies; FR – Family reaction; CD – Communication difficulty; OT – Other mixed worries

Overall, majority of the caregiver's worries were in the other mixed worries (47%) like travelling, safety needs of the child, problem behavior management, information discrepancy, lack of boundaries, lack of knowledge about aids and therapy success etc as compared to family stress (31%), communication difficulty (11%), parenting discrepancies (6%) and family reactions (5%). A total of 11 questions out of 68 were removed primarily because of their cultural irrelevance. The questions which were removed are shown in Table 4.2.

Table4.2

Questions which are culturally loaded

02	Child care providers/schools/teachers/out-of-home caregiver's lack of signing skills.
21	Worries about deaf community's perception of my decisions for my child.
22	Lack of interpreters of child.
25	My lack of signing skills.
28	Inadequate insurance coverage for treatment of hearing impairment.
36	My child's lack of signing skills.
39	Problems dealing with insurance company.
47	Healthcare provider's lack of signing skills.
58	Immediately family and relative's lack of signing skills.
61	Costly daily aids like vibrating alarms and TTY services.
67	Lack of large deaf community.

In the discussion that follows, the emerged themes were operationally defined for the purpose of the current study considering the cultural relevance.

Table 4.3

Themes emerged, definitions and responses of the caregiver's.

Themes emerged	**Definition**	**Responses**
Family stress	Lack of cohesion due to separation, financial crisis, unemployment, death or divorce, child care or any chronic illness/disability.	*Have to stop working because of child.* *Feels sometimes bad that i have no time for myself.* *Have to spend all the time for the child* *Have to be with the child always , cannot leave alone* *Not able to be with their family members.*
Family Reaction	Severe expressed emotions towards the family and the child with disability like refusal, rejection, comparison, refusing opportunity.	*Feels bad that no adequate support from spouse and family members* *Have to hear positive and negative comments from family members* *Worries how my family looks at my child's disability* *Worries about family not supporting much for the child*
Parenting Discrepancies	Differing parenting style and expectation.	*Feels that they are responsible for child's loss and they think because of consanguineous marriage.* *Have shifted to other place because of child.* *No support from spouse*
Communication difficulty	Difficulty in meeting communication needs with the child.	*Difficulty in communicating with the child* *Worries that how to make the child understand.* *Worries by seeing other hearing peers using signs to communicate with my child.* *Worries about the child's emotional expression*

Other mixed worries	Concerned about child’s social adjustment, social competence, learning, meeting safety needs of the child	*Costly medical equipments* *Worries about safety issues* *Problem with travelling for therapy.* *Worries about child’s future* *Worries about others taking advantage of the child*

4.2 Quantitative Analysis

4.2.1 Demographic characteristics: Of the 100 caregiver’s who were included in the analysis; all of the questionnaires were filled out by mothers of children with hearing impairment. All of the caregiver’s were normal hearing individuals. The mean age of child at the time of study was 4.8 (±1.5) years while mean age at the diagnosis of hearing loss was 22 (±12.9) months. The mean age of the caregiver was 28 (±3.01) years. All of the children were diagnosed as bilateral permanent hearing loss of varying degrees and were using either Bilateral Hearing aids or Cochlear implant in one ear and hearing aid in the other ear.

Table 4.4

Demographic characteristics of child and caregiver(quantitative study)

	Mean (SD)	**Frequency (%)**
Child Demographics		
Age	4.68 (1.5)	-
Age of identification of HL	22.04 (12.9)	-
Degree of HL		-
Moderate	-	2 (2)
Moderately Severe	-	5 (5)
Severe	-	20 (20)
Profound	-	73 (73)

Caregiver Demographics		
Age	28.19 (3.01)	-
Domicile		
Rural	-	66 (66)
Urban	-	34 (34)
Education	-	
Primary and below primary	-	20 (20)
Secondary and above	-	71 (71)
Undergraduate and above	-	09 (09)
Occupation		
Employed		5 (5)
Unemployed	-	95 (95)
Family Type	-	
Nuclear	-	43 (43)
Joint	-	57 (57)

Table 4.4 represents the subject and caregiver’s characteristics. Majority of the children were diagnosed as permanent profound degree of hearing loss (73%) as compared to severe (20%), moderately severe (5%) and moderate (2%) degree of hearing loss. Majority of the caregiver’s of hearing impaired education was till secondary and above (71%) as compared to primary and below primary (20%) and undergraduate and above (9%). Most of the caregiver’s been unemployed (95%) and belongs to rural area (66%) as compared to employed caregiver’s (5%) and belongs to urban area (34%). Majority of the family type was joint family (57%) as compared to nuclear family (43%).

4.2.2 Caregiver's stress: The results of the study are being presented under the following conditions:

4.2.2.1 Frequency distribution of stressors reported by caregivers in Adapted PHICE

4.2.2.2 Statistical analysis to find the difference between various demographic variables with respect to the total scores on adapted PHICE.

4.2.2.1 Frequency distribution of stressors reported by caregivers in Adapted PHICE of children with hearing impairment: The following table represents stressors reported by caregivers of children with hearing impairment. It is meaningful to note that the following reports of the parent on adapted PHICE plays a vital role in the clinical counseling during the primary phase of the diagnosis. Also, it can be inferred that the support system from family, community and professionals has to consider.

Table 4.5

Stressors reported among caregivers of children with hearing impairment

Items on PHICE	**N (%)**
Worries about my child's safety	70(70)
Worries about how my child fits into the hearing community	61(61)
Feeling uncertain about my child's future	60(60)
Worries about decisions I have made for my child	59 (59)
Worries about others taking advantage of my child	57 (57)
Relocation to be near resources that meet my child' s special needs	53 (53)
Costly medical equipment and expenses	50 (50)
Seeing my child frustrated because of his/her hearing loss	50 (50)

Worries about not doing enough for child	44 (44)
Worries about choosing the best form of communication for the child	43 (43)

** Note: Responses in high stress were considered*

4.2.2.2Statistical analysis to find the difference between various demographic variables with respect to the total scores on adapted PHICE: The mean and the standard deviation of the total score of the adapted PHICE is 98.94 (±15.49) respectively. The +1SD and +2 SD of the PHICE score are 114 and 129 respectively and the -1SD and -2 SD of the PHICE score are 84 and 69 respectively. Hence, six groups were made based on the mean and -1, -2, +1 and +2 standard deviation from the mean. The frequency distribution of the score based on the mean and standard deviation on the PHICE is represented in table 4.6. It is clear from the table that majority of the caregiver's had scores on the adapted PHICE around 100-114 (42%) as compared to 85-99 (35%), 115-129 (12%), 0-69 (7%) and 70-84 (4%).

Table 4.6

PHICE score groups

Groups	**N (%)**
0-69	07 (07)
70-84	04 (04)
85-99	35 (35)
100-114	42 (42)
115-129	12 (12)
130-171	0

Table 4.7

Mean (±SD) score on Age of identification with respect to parents score in adapted PHICE.

Variable	**N**	**Mean (SD)**	**t**	**df**	**'p'**
Ageofidentification (Months)					
<24	76	99.750 (14.518)	**0.929**	**98**	**0.355**
>24	24	96.375 (18.372)			

The independent t-test was carried out to identify the differences between age of identification of hearing loss with total score on the adapted PHICE. The results reveal that there is no significant difference between variables (p>0.05). The results are represented in Table 4.7.

Table 4.8

Mean (±SD) score on domicile with respect to parents score in adapted PHICE.

Variable	**N**	**Mean (SD)**	**t**	**df**	**'p'**
Domicile					
Rural	66	99.318 (15.888)	0.338	98	0.735
Urban	34	98.205 (14.917)			

The independent t-test was carried out to identify the differences between domicile with total score on the adapted PHICE. The results reveal that there is no significant difference between variable(p>0.05). The results are represented in Table 4.8.

Table 4.9

Mean (±SD) score on Family type with respect to parents score in adapted PHICE

Variable	N	Mean (SD)	t	df	'p'
Family type			**1.969**	**98**	**0.051**
Nuclear	43	102.162 (15.324)			
Joint	57	96.508 (15.313)			

The independent t-test was carried out to identify the differences between family types with total score on the adapted PHICE. The results reveal that there is no significant difference between variables (p>0.05). The results are represented in Table 4.9.

Table 4.10

Mean (±SD) score on level of education with respect to parents score in adapted PHICE.

Variable	**N**	**Mean (SD)**	**F**	**df**	**'p'**
Education					
Primary and below	20	96.100 (17.136)			
Secondary and above	44	97.204 (16.621)	1.659	2	0.196
UG and above	36	102.638 (12.574)			

The one way ANOVA was carried out to identify the differences between levels of caregiver's education with total score on the adapted PHICE. The results reveal that there is no significant difference between variables($p>0.05$). The results are represented in Table 4.10.

Chapter 5

Discussion

Stress is a complex phenomenon with physiological and psychological impacts. Also, it is culturally intertwined with many demographic variables like type of family, cultural value, societal expectation, community participation etc. within which the disability on the other hand have evident impact on oneself, family and community. Specifically, hearing impairment or hard of hearing interferes with all the variables. Alongside, the caregiver’s of children with hearing impairment experiences tremendous changes in the family, attitude, attachment, needs of the family, coping mechanisms of the family. It is essential to understand these impacts during therapy process.

The results from the current study demonstrate the highly loaded stress factors related to rearing the child with hearing impairment. Also, it is evident from the results that the support system to the caregiver’s of children with hearing impairment play a significant role in coping up with the stress. Current study involved parents who were pre-exposed to supportive environment like therapy, special educational environment, supportive families with similar conditions ease the coping mechanism.

The results of the present study shows that the most of the caregiver’s reported stress related to child’s safety, uncertainty of child’s future, others taking advantage of child with hearing impaired, seeing child frustrated, relocation of the resources and difficulty in choosing the best form communication. The stresses were concerned to different domains like travelling, finance, emotional well-being of mother and communication. The study reported by Meinzen-Derr et al., (2008) that the effect of duration since the diagnosis, communication difficulties, education, support system, health and emotional well-being escalates the stress among caregiver's. Duration since the diagnosis of hearing impairment in children change the way of coping.

It is also observed in the current study that the selected demographic variables showed no significant relationship with the caregiver's stress experiences. Similarly, the study done by Konstanttareas&Lamppropoulou (1995), who reported that maternal age, education level were unrelated to stress experienced by caregiver's. However, in the same study the results revealed the significant relationship between the child characteristics like age of onset of deafness (prior to 18 months of age) was found to have relation with caregiver's stress experience.

Chapter 6

Summary and conclusion

In general, caregiver's of children with hearing impairment experiences stress related to child needs and societal demands. Demographic characteristics did not have significant effect on the caregiver's stress. PHICE can be used as effective tool to measure the experiences of caregiver's of children with hearing impairment.

In conclusion, PHICE can be used to deliver a comprehensive therapy for caregiver's of children with hearing impairment and child by understanding the caregiver's experiences.

6.1 Utility of the study:

1. Professionals understanding of the stress related factors experienced by caregiver's may help in effective counseling which might bring the overall development of the child which may enhance the therapeutic compliance and the development of the child.
2. Comprehensive assessment of caregiver's of children with hearing impairment enhances the therapeutic compliance and the development of the child.

6.2 Limitations of the study

1. Relatively sample size is small.
2. Domains emerged in the Phase I of the study was not carried out in the study due to lack of representation of sample in each domain.
3. Majority of the children were profound degree of impairment.
4. Lack of psychometric properties of the tool in the cultural context.

5. It is possible that parents of children with moderate, severe and profound loss may have higher level of stress which is not tapped in the study.
6. Prior exposure to support environment to parents of children with hearing loss might have impact on the study.
7. In the present study there were over representation of participants who were unemployed.

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APPENDIX

ಕಿವಿಕೇಳದಿರುವಮಕ್ಕಳಪೋಷಕರು / ಆರೈಕೆನೀಡುವವರಅನುಭವ
ಪೋಷಕರಿಗೆ / ಆರೈಕೆನೀಡುವವರಿಗೆಪ್ರಶ್ನಾವಳಿ

ಕಿವಿಕೇಳದಿರುವಮಕ್ಕಳಪೋಷಕರುಅಥವಾಆರೈಕೆನೀಡುವವರುಎದುರಿಸುವಸಂಭವನೀಯಸಮಸ್ಯೆಗಳಪಟ್ಟಿಈಕೆಳಗಿನಂತಿದೆ.
ನೀವುಕಳೆದಆರುತಿಂಗಳುಗಳಲ್ಲಿಅನುಭವಿಸಿದಒತ್ತಡದಬಗ್ಗೆಯೋಚಿಸಿನಮಗೆತಿಳಿಸಿ,
ಈಪ್ರಶ್ನಾವಳಿಗೆಉತ್ತರಿಸುವಾಗನಿಮ್ಮಮಗುವಿನಕಿವಿಕೇಳದಿರುವಿಕೆಯಪರಿಣಾಮವಾಗಿನೀವುಅನುಭವಿಸಿದಿರುವುದನ್ನುತಿಳಿಸಿ. ಇದುನಿಮ್ಮಸಮಸ್ಯೆಆಗದಿದ್ದಲ್ಲಿಅಥವಾನಿಮ್ಮಮಗುವಿಗೆಸಂಬಂಧಿಸದಿದ್ದರೆ, ಪಟ್ಟಿಯಲ್ಲಿ "ಅನ್ವಯಿಸುವುದಿಲ್ಲ" ಎಂಬುದಕ್ಕೆಗುರುತುಹಾಕಿ.
ನೀವುಒಂದಕ್ಕಿಂತಹೆಚ್ಚುಮಗುವನ್ನುಹೊಂದಿದ್ದರೆನಿಮ್ಮಹಿರಿಯಮಗುವಿನಕೇಳದಿರುವಿಕೆಯಸಮಸ್ಯೆಯನ್ನುಕುರಿತುಈಪ್ರಶ್ನಾವಳಿಗೆಉತ್ತರಿಸಿ.

ನೀವುಕಳೆದಆರುತಿಂಗಳಲ್ಲಿಅನುಭವಿಸಿದಒತ್ತಡದಮಟ್ಟದಲ್ಲಿಈಕೆಳಗಿನವುಗಳುಯಾವುದಾದರೂಇದ್ದರೆ, ಗುರುತಿಸಿ:	ಅನ್ವಯಿಸುವುದಿಲ್ಲ	ಒತ್ತಡಇಲ್ಲದಿರುವಿಕೆ	ತೀರಕಡಿಮೆಒತ್ತಡ	ಕಡಿಮೆಒತ್ತಡ	ಮಧ್ಯಮಒತ್ತಡ	ಹೆಚ್ಚುಒತ್ತಡ	ಅತಿಹೆಚ್ಚುಒತ್ತಡ	ತೀರಅತಿಹೆಚ್ಚುಒತ್ತಡ
1. ಕೇಳುವನಷ್ಟದಿಂದಮಗುಉದ್ವೇಗಕೋಪೋದ್ರೇಕಗಳುಹೊಂದಿದೆ (ಹೆಚ್ಚುಕೋಪ)	1	2	3	4	5	6	7	8
2. ಶೈಕ್ಷಣಿಕಅರ್ಹತೆವೃತ್ತಿಪರರೊಂದಿಗೆಕಾರ್ಯನಿರ್ವಹಿಸುವಿಕೆ	1	2	3	4	5	6	7	8
3. ಅವನು / ಅವಳುತನ್ನಉಪಕರಣವನ್ನುಕಳೆದುಕೊಳ್ಳುವಅಥವಾಹಾನಿಗೊಳಗಾಗುವಬಗ್ಗೆಚಿಂತೆ	1	2	3	4	5	6	7	8
4. ಕೆಲಸಕ್ಕೆಹೋಗಲುಸಾಧ್ಯವಾಗುತ್ತಿಲ್ಲ	1	2	3	4	5	6	7	8
5. ನನ್ನಮಗುವಿಗೆಕಿವಿಕೇಳುವುದಿಲ್ಲಎಂದುಒಪ್ಪಿಕೊಳ್ಳುವುದುಕಷ್ಟಕರವಾಗಿದೆ.	1	2	3	4	5	6	7	8
6. ಕಿವಿಕೇಳುವಸಾಧನಗಳುಅಥವಾಕೊಕ್ಲೀಯರ್ಇಂಪ್ಲಾಂ	1	2	3	4	5	6	7	8

ಟ್ಸ್ನಿಂದನಿರೀಕ್ಷಿಸಿದಷ್ಟುದೊರೆಯುತ್ತಿಲ್ಲ.								
7.ವಿಳಂಬಗೊಂಡಕೋಕ್ಲೀಯರ್ಇಂಪ್ಲಾಂಟೇಶನ್.	1	2	3	4	5	6	7	8
8. ಆರೋಗ್ಯಪೂರೈಕೆದಾರರುನನ್ನಮಾತನ್ನುಕೇಳುತ್ತಿಲ್ಲಎಂಬಭಾವನೆ	1	2	3	4	5	6	7	8
09. ಉದ್ಯೋಗದಾತರಿಂದಸರಿಯಾದಬೆಂಬಲಮತ್ತುತಿಳುವಳಿಕೆಇಲ್ಲದಿರುವಿಕೆ	1	2	3	4	5	6	7	8
10. ಮಗುಕಿವಿಕೇಳದಿರುವಿಕೆಯನ್ನುಬಳಸಿಕೊಂಡುಕೆಟ್ಟದಾಗಿವರ್ತಿಸುತ್ತದೆ.	1	2	3	4	5	6	7	8
11. ನನ್ನಮಗುವಿನಭವಿಷ್ಯದಬಗ್ಗೆಅನಿಶ್ಚಿತತೆಯಭಾವನೆಯಅನುಭವ.	1	2	3	4	5	6	7	8
12. ಮಗುವಿನಜೋರಾದಧ್ವನಿಯಿಂದಕಿರಿಕಿರಿಮತ್ತುಕಿರುಚಿದಂತೆಆಗುತ್ತದೆ.	1	2	3	4	5	6	7	8
13. ನಡವಳಿಕೆಮತ್ತುಸಂವಹನಸಮಸ್ಯೆಗಳವ್ಯತ್ಯಾಸತಿಳಿದುಕೊಳ್ಳುವಿಕೆ	1	2	3	4	5	6	7	8
14. ಮಗುವಿಗೆವಿಶೇಷಕಲಿಕೆಯವಸ್ತುಗಳನ್ನುಪಡೆದುಕೊಳ್ಳುವುದು (ಪುಸ್ತಕಗಳು, ಶಿರೋನಾಮೆಯವೀಡಿಯೊಗಳು)	1	2	3	4	5	6	7	8
15. ಮಕ್ಕಳಚಟುವಟಿಕೆಗಳನಡುವೆಪ್ರವೇಶಿಸುವಸಾಧನಗಳು.	1	2	3	4	5	6	7	8
16. ಮಗುವಿಗೆಸಾಕಷ್ಟುಆರೈಕೆಮಾಡುತ್ತಿಲ್ಲವೆಂದುಚಿಂತೆ	1	2	3	4	5	6	7	8
17. ಕುಟುಂಬದಇತರೆಸದಸ್ಯರಅಗತ್ಯಗಳನ್ನುಪೂರೈಸಲುಆಗುತ್ತಿಲ್ಲ.	1	2	3	4	5	6	7	8
18. ನನ್ನಮಗುವಿಗೆಒಳ್ಳೆಯವೈದ್ಯಕೀಯಆರೈಕೆಆಗುತ್ತಿದೆಯೋಇಲ್ಲವೋಎಂಬಚಿಂತೆ.	1	2	3	4	5	6	7	8
19. ವೈದ್ಯರೊಂದಿಗೆಕಾರ್ಯನಿರ್ವಹಿಸುವಿಕೆ.	1	2	3	4	5	6	7	8
20. ಇತರರುನನ್ನಮಗುವಿನಪ್ರಯೋಜನವನ್ನುಪಡೆಯುವಬ	1	2	3	4	5	6	7	8

ಗ್ಗೆಚಿಂತೆ								
21. ನನ್ನಮಗುವಿನಸುರಕ್ಷತೆಯಬಗ್ಗೆಚಿಂತೆ.	1	2	3	4	5	6	7	8
22. ಅತ್ಯುತ್ತಮಸಂವಹನದರೂಪವನ್ನುಆಯ್ಕೆಮಾಡುವಬಗ್ಗೆ ಚಿಂತೆ (ಮೌಖಿಕ, ಚಿಹ್ನೆ, ಒಟ್ಟು).	1	2	3	4	5	6	7	8
23. ಮಗುವಿನಶಿಕ್ಷಣದಬಗ್ಗೆಮಾಡಿದನಿರ್ಧಾರಗಳಬಗ್ಗೆಚಿಂತೆ	1	2	3	4	5	6	7	8
24. ಮಗುವಿನಕೇಳದಿರುವಿಕೆಗೆಭಾಗಶಃನನ್ನಹೊಣೆಗಾರಿಕೆಕಾರಣವಾಗಿದೆ	1	2	3	4	5	6	7	8
25. ಮಗುವಿನಶಿಸ್ತಿನಬಗ್ಗೆಅನಿಶ್ಚಿತತೆಯಭಾವನೆ	1	2	3	4	5	6	7	8
26. ವೈದ್ಯಕೀಯಚಿಕಿತ್ಸೆಗಳಿಗೆಪ್ರಯಾಣ.	1	2	3	4	5	6	7	8
27. ವೈದ್ಯಕೀಯಮಾಹಿತಿಯಿಂದಗೊಂದಲಕ್ಕೊಳಗಾದಭಾವನೆ	1	2	3	4	5	6	7	8
28. ಕೆಲಸದಒತ್ತಡದಿಂದಮಗುವಿನಅಗತ್ಯಗಳಿಗೆಸಮಯವನ್ನುತೆಗೆದುಕೊಳ್ಳಲುಆಗುತ್ತಿಲ್ಲ.	1	2	3	4	5	6	7	8
29. ಮಗುವಿನಆರೈಕೆಅಥವಾಶಿಶುವಿಹಾರದಕೊರತೆ.	1	2	3	4	5	6	7	8
30. ನನ್ನಮಗುಸ್ನೇಹಸಾಮರ್ಥ್ಯಬೆಳಸಿಕೊಳ್ಳದಿರುವಬಗ್ಗೆಚಿಂತೆ	1	2	3	4	5	6	7	8
31. ನನ್ನಮಗುವಿನೊಂದಿಗೆಸಂವಹನದತೊಂದರೆ.	1	2	3	4	5	6	7	8
32. ಶಾಲೆಯಲ್ಲಿಮಗುವಿನವರ್ತನೆ	1	2	3	4	5	6	7	8
33. ಮಗುವಿನಕೇಳದಿರುವಿಕೆಯಸಮಸ್ಯೆಯಿಂದಆಯಾಸಗೊಂಡಭಾವನೆ	1	2	3	4	5	6	7	8
34. ನನ್ನಕುಟುಂಬದೊಂದಿಗೆಮತ್ತುಸಂಬಂಧಿಕರೊಂದಿಗೆಬದಲಾದಸಂಬಂಧಗಳು	1	2	3	4	5	6	7	8
35. ಹೆಚ್ಚಿನಸಂಖ್ಯೆಯಲ್ಲಿವೈದ್ಯಕೀಯಚಿಕಿತ್ಸೆಗಳನಿರ್ವಹಣೆ	1	2	3	4	5	6	7	8
36. ಶುಶ್ರೂಷಕಿಅಥವಾಪುನರ್ವಸತಿತಂಡದೊಂದಿಗೆಕಾರ್ಯ	1	2	3	4	5	6	7	8

ನಿರ್ವಹಣೆ.								
37. ಕೇಳದಿರುವಿಕೆಯತೊಂದರೆಗೆಸಂಬಂಧಿಸಿದಕಾನೂನುಗಳಬಗ್ಗೆತಿಳಿದುಕೊಳ್ಳುವಿಕೆ	1	2	3	4	5	6	7	8
38. ಕೇಳದಿರುವಿಕೆಯತೊಂದರೆಅಥವಾಪುನರ್ವಸತಿಬಗ್ಗೆ ಮಾಹಿತಿಪಡೆಯುವಲ್ಲಿತೊಂದರೆ	1	2	3	4	5	6	7	8
39. ಕೇಳುಗರಸಮೂದಾಯದಲ್ಲಿನನ್ನಮಗುಹೇಗೆವರ್ತಿಸುವುದುಎಂಬುದರಬಗ್ಗೆಚಿಂತೆ	1	2	3	4	5	6	7	8
40. ಶಾಲೆಯಲ್ಲಿಮಗುವಿನಶೈಕ್ಷಣಿಕಸಾಧನೆ.	1	2	3	4	5	6	7	8
41. ನನ್ನಮಗುವಿಗೆಶೈಕ್ಷಣಿಕಅವಕಾಶಗಳಕೊರತೆ	1	2	3	4	5	6	7	8
42. ವೆಚ್ಚದಾಯಕವೈದ್ಯಕೀಯಉಪಕರಣಗಳುಮತ್ತುವೆಚ್ಚಗಳು.	1	2	3	4	5	6	7	8
43. ನನಗೆನನಗೋಸ್ಕರಸಮಯವಿಲ್ಲದಿರುವಿಕೆ.	1	2	3	4	5	6	7	8
44. ಮಗುವಿಗೆಕೇಳದಿರುವಿಕೆಯದುರ್ಬಲತೆಯಆರೈಕೆಯ ಮಾಹಿತಿಯಿಂದಯೋಚನೆಯಾಗಿದೆ.	1	2	3	4	5	6	7	8
45. ವೈದ್ಯಕೀಯಮತ್ತುಪುನರ್ವಸತಿಆರೈಕೆಪಡೆಯುವಲ್ಲಿ ತೊಂದರೆ	1	2	3	4	5	6	7	8
46.ನನ್ನಮಗುವಿಗೆಕೇಳಿಸಿಕೊಳ್ಳಲುಕೇಳುವಿಕೆಯಸಾಧನ, ಕೊಕ್ಲೀಯರ್ಇಂಪ್ಲಾಂಟ್, ಅಥವಾಯಾವುದೇಸಾಧನೆಬೇಕಾಗಬಹುದುಎಂಬುವುದರಬಗ್ಗೆಚಿಂತೆ	1	2	3	4	5	6	7	8
47. ಕುಟುಂಬದವರಿಂದಮತ್ತುಸಂಬಂಧಿಗಳಿಂದಬೆಂಬಲಮತ್ತುತಿಳುವಳಿಕೆಯಕೊರತೆ.	1	2	3	4	5	6	7	8
48. ಇದೇರೀತಿಯತೊಂದರೆಗಳನ್ನಅನುಭವಿಸುತ್ತಿರುವಪೋಷಕರಸಂಘಮತ್ತುಬೆಂಬಲದಕೊರತೆ.	1	2	3	4	5	6	7	8
49. ಮಗುವಿನೊಂದಿಗೆಲೈಂಗಿಕಸಮಸ್ಯೆಗಳನ್ನುಚರ್ಚಿಸು	1	2	3	4	5	6	7	8

ವತೊಂದರೆಗಳು								
50. ಮಗುವಿನಓದುವಸಾಮರ್ಥ್ಯ.	1	2	3	4	5	6	7	8
51. ಕೇಳುವಿಕೆಯಸಾಧನಅಥವಾಕಸಿಮಾಡಿಸಿರುವುದರಆರೈಕೆ.	1	2	3	4	5	6	7	8
52. ಮಗುವಿನವಿಶೇಷಅಗತ್ಯತೆಗಳಿಗೆಭೇಟಿನೀಡಲುಹತ್ತಿರದ ಸಂಪನ್ಮೂಲಗಳಿಗೆಸ್ಥಳಾಂತರಿಸುವುದು	1	2	3	4	5	6	7	8
53. ವೈದ್ಯಕೀಯಚಿಕಿತ್ಸೆಗೆಸಂಬಂಧಿಸಿದಅಪಾಯಗಳಬಗ್ಗೆ ಚಿಂತೆ (ಉದಾ: ಶಸ್ತ್ರಚಿಕಿತ್ಸೆ, ಕೇಳುವಿಕೆಯಉಪಕರಣ).	1	2	3	4	5	6	7	8
54. ನನ್ನಮಗುವಿಗೆಕೇಳದಿರುವಿಕೆಯತೊಂದರೆಇರುವಬಗ್ಗೆವಿಳಂಬವಾಗಿತಿಳಿದಿರುವುದು.	1	2	3	4	5	6	7	8
55. ನನ್ನಮಗುವಿನಚಿಕಿತ್ಸೆಅಥವಾಪುನರ್ವಸತಿಯಯಶಸ್ಸಿನಬಗ್ಗೆಚಿಂತೆ	1	2	3	4	5	6	7	8
56. ಸ್ನೇಹಿತರುಮತ್ತುಸಂಬಂಧಿಗಳಿಂದಬೆಂಬಲಅಥವಾತಿಳುವಳಿಕೆಯಕೊರತೆ.	1	2	3	4	5	6	7	8
57. ಮಗುಕೇಳದಿರುವಿಕೆಯತೊಂದರೆಯಿಂದಅವನ / ಅವಳುಅನುಭವಿಸುವಹಿಂಜರಿಕೆ	1	2	3	4	5	6	7	8