

## Validation of the Paediatric Hearing Impairment Caregiver Experience (PHICE) Questionnaire

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### Abstract

**Introduction:** The paediatric hearing impairment caregiver experience (PHICE) questionnaire is a 68-item instrument that assesses the stress experienced by caregivers of children with hearing impairment (HI). While the questionnaire has been validated in the United States, it may need to be modified for use in the Singapore context due to the differing healthcare system, costing and culture related to caregiving for children with HI. This study aims to modify and validate the PHICE questionnaire to increase its relevance and ease of use in Singapore. **Materials and Methods:** The original PHICE questionnaire was filled out by 127 caregivers of HI children managed at the otolaryngology clinic of the National University Hospital (NUH). An expert panel was convened to assess the questionnaire for its suitability for use in Singapore. Exploratory factor analysis was conducted to evaluate the underlying factor structure of the original PHICE questionnaire. Items with high cross-loadings were removed and a new factor structure was adopted which was further analysed using confirmatory factor analysis (CFA). Cronbach's alpha ( $\alpha$ ) was computed to determine the internal consistency of the new subscales. **Results:** Items that are less relevant in Singapore and those with high cross-loadings were removed. A 5-factor structure with only 42 items remaining and corresponding to the factors: "Policy", "Healthcare", "Education", "Support" and "Adaptation" was adopted. CFA suggests a good model fit for the modified questionnaire, improved from the 8-factor structure of the original PHICE. Cronbach's  $\alpha$  were high ( $>0.7$ ) for each new subscale. **Conclusion:** The original PHICE questionnaire has been shortened and reorganised in terms of the subscales composition. The resulting instrument is structurally valid and internally consistent. It is a simple and useful tool for identifying factors related to caregiving that can negatively impact rehabilitation outcomes for children with HI in Singapore. Removal of some sign language items makes this modified version less useful for caregivers, places or countries where sign language is the main focus of rehabilitation for children with HI.

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**Key words:** Modified, Outcome, Rehabilitation, Stress

### Introduction

The stress experienced by parents of children with hearing impairment (HI) has been studied over the past 2 decades. Increased parenting stress is often associated with developmental problems such as delay in language acquisition, social and emotional problems.<sup>1,2</sup> The stress that parents endure fluctuates as they go through the process of meeting and overcoming various challenges associated with their child's HI.<sup>3-8</sup> Increased caregiver stress has been correlated with poorer health functioning outcomes for the child. If healthcare teams can identify the domains of caregiver stress and tailor efforts to mitigate the most important stressors specific to each caregiver, hearing outcomes of the child may also be improved.

The paediatric hearing impairment caregiver experience (PHICE) questionnaire has previously been developed to document the various stressors caregivers may experience related to their child's HI.<sup>9</sup> PHICE is a 68-item instrument spanning 8 factors of stress: 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). The item is scored on an 8-point Likert scale with the descriptors: "Not applicable", "No stress", "Very low stress", "Low stress", "Moderate stress", "High stress", "Very high stress" and "Extremely high stress". While this instrument has been validated in the United States, it may need to be modified for use in the Singapore context due to

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the differing healthcare system, costing and culture related to caregiving for children with HI. The questionnaire takes about 25 minutes to complete.

This study aims to modify, shorten and validate the PHICE questionnaire to increase its relevance and ease of use in Singapore. As the data used to shorten the questionnaire is collected in Singapore, the validity of the shortened version would be assessed in a Singapore context.

## Materials and Methods

### *Participants*

A total of 127 caregivers of children with permanent HI who had been receiving treatment at the Otolaryngology – Head and Neck Surgery Centre of the National University Hospital (NUH) were recruited for the study. Caregiver was defined as a parent, family member or other personnel who takes care of the child with HI. The children were managed at the clinic by otolaryngologists, audiologists, speech and language therapists, auditory-verbal therapists, and multidisciplinary supporting specialists as appropriate. Informed consent was sought and the original 68-item PHICE questionnaire was administered to the caregiver.

### *Expert Panel Review*

An expert panel was convened to assess each item on the original PHICE questionnaire for its suitability for use in Singapore. The expert panel consisted of an otolaryngology surgeon, an audiologist and 2 speech and language/auditory-verbal therapists. Items that were less relevant to the Singapore context were removed. The expert panel has had vast experience with management of children with HI and their caregivers in the Singapore context.

### *Data Analysis*

Data analysis was conducted on the remaining items through R.<sup>10</sup> Missing data was imputed by cross-validation imputation using the package “missMDA”.<sup>11,12</sup> The amount of missing data was deemed to be small at 0.72%. The imputed data was rounded off to the nearest integer to maintain the ordinal nature of the scale and to make the data interpretable.<sup>13</sup> The items were recoded such that the “Not applicable” entries were mapped to “No stress”. This is on the assumption that if an item is not applicable to a caregiver, the caregiver has not faced stress in that particular area. This recoding preserves the inherent assumption of equidistant between points on the Likert scale.

Factor analysis was conducted using the package “psych”.<sup>14</sup> Factor analysis is a group of methods that aims to understand the underlying structure of the variables. In the current study, the variables are the items of the PHICE

questionnaire and there is an assumed structure of these variables denoted by their subscales. This assumed structure was derived from expert opinion. The purpose of factor analysis is to validate this opinion or propose an alternative way of grouping the items by analysing the mathematical relationships between the items.<sup>15</sup>

Factor analysis was conducted using principal axis factoring (PAF) as we do not want to simply account for all the variance of the items, but are interested in shared variance of the items.<sup>16</sup> This orientation allows us to cater for other sources of variance (e.g. random error) and is more compatible with classical test theory.<sup>17</sup> Oblique rotation was used as the latent factors are expected to correlate with each other.<sup>18</sup> Oblimin was selected as the rotation of choice as it provides flexibility to vary the intercorrelations amongst factors.<sup>18</sup> Non-graphical solutions to the scree test including eigenvalues, parallel analysis, optimal coordinates, and acceleration factor were used to help determine the appropriate number of factors to retain.<sup>19-20</sup> These analyses were conducted using “nFactors” through R.<sup>21</sup> Cross-loadings for each item were assessed. A cross-loading difference of less than 0.1 between the 2 highest factors loading was set as the criteria for removal of items. High cross-loading suggests that an item can possibly lie in more than one domain and thus is ambiguous in the actual latent construct it represents. Given the ambiguity, we decided to exclude the items in the shortened version.

Confirmatory factor analysis (CFA) was conducted on the original and new factor models. Goodness-of-fit indices were assessed to evaluate if there is an improvement in the fit of the model. Cronbach’s alpha ( $\alpha$ ) was computed for the new subscales to determine its internal consistency.

## Results

### *Demographics*

A total of 127 PHICE questionnaires were collected between April 2004 and March 2009. Two questionnaires were excluded from analysis as they were largely unfilled. The majority of the questionnaires (78%) were filled out by a mother, 20% of them were filled out by a father, and the rest were filled out by a grandparent or other relatives.

Table 1 shows the demographic, audiological and functioning profile for both the caregivers and their children with different types of hearing devices. The children’s ages ranged from 3 months to 18 years, with an average age of 6 years (median, 5 years). Regarding the type of hearing device used, 9.6% ( $n = 12$ ) of the children were not aided with any device, 65.6% ( $n = 82$ ) were aided with hearing aid (HA), 13.6% ( $n = 17$ ) were aided with cochlear implant (CI) and HA on different ears, and 11.2% ( $n = 14$ ) were aided with CI only. The degree of hearing loss, social

Table 1. Demographic, Audiological and Functioning Profile of Caregivers and Their Children with Hearing Loss

	Type of Hearing Devices			
	No Aid, n = 12	HA, n = 82	CI + HA, n = 17	CI, n = 14
<b>Children with hearing loss</b>				
Male (%)	7 (58.3)	47 (57.3)	12 (70.6)	7 (50)
Age of hearing loss diagnosis (months)	49 (0 – 144)	33 (0 – 180)	29 (1 – 46)	15 (1 – 41)
Age at the time of study (months)	87 (14 – 192)	87 (3 – 226)	78 (26 – 133)	56 (27 – 97)
Degree of hearing loss (defined by hearing in the better ear)*				
None (unilateral hearing loss)	3 (25.0)	5 (6.1)	0 (0)	0 (0)
Mild	4 (33.3)	15 (18.3)	0 (0)	0 (0)
Moderate	2 (16.7)	22 (26.8)	1 (5.9)	0 (0)
Moderately severe	0 (0)	3 (3.6)	1 (5.9)	0 (0)
Severe	0 (0)	32 (39.0)	13 (76.5)	9 (64.3)
Profound	0 (0)	1 (1.2)	2 (11.7)	5 (35.7)
Usefulness of hearing device				
Not very	NA	10 (12.2)	1 (5.9)	2 (14.3)
Somewhat	NA	21 (25.6)	2 (11.8)	1 (7.1)
Very	NA	24 (29.3)	11 (64.7)	3 (21.4)
Extremely	NA	21 (25.6)	3 (17.6)	8 (57.1)
Social functioning*				
Poor	0 (0)	5 (6.1)	0 (0)	0 (0)
Fair	4 (33.3)	22 (26.8)	4 (23.5)	1 (7.1)
Good	4 (33.3)	26 (31.7)	6 (35.3)	4 (28.6)
Very good	2 (16.7)	17 (20.7)	4 (23.5)	3 (21.4)
Excellent	0 (0)	7 (8.5)	2 (11.8)	6 (42.9)
Academic functioning*				
Poor	2 (16.7)	17 (20.7)	0 (0)	0 (0)
Fair	3 (25.0)	20 (24.4)	6 (35.3)	3 (21.4)
Good	2 (16.7)	18 (22.0)	6 (35.3)	4 (28.6)
Very good	1 (8.3)	8 (9.8)	2 (11.8)	3 (21.4)
Excellent	0 (0)	3 (3.6)	0 (0)	2 (14.3)
<b>Caregivers of children with hearing loss</b>				
Male (%)	1 (8.3)	17 (20.7)	4 (23.5)	3 (21.4)
Age (years)*	35 (29 – 43)	39 (25 – 62)	39 (25 – 50)	33 (25 – 44)
Education level				
Primary or lower	1 (8.3)	7 (8.5)	1 (5.9)	0 (0)
Secondary	4 (33.3)	17 (20.7)	3 (17.6)	4 (28.6)
High school or college	4 (33.3)	38 (46.3)	9 (52.9)	7 (50.0)
Degree or higher	3 (25.0)	16 (19.5)	4 (23.5)	2 (14.3)
Involvement in child's rehabilitation				
None	3 (25.0)	7 (8.5)	0 (0)	0 (0)
Some	2 (16.7)	29 (35.4)	6 (35.3)	5 (35.7)
Mostly	7 (58.3)	43 (52.4)	11 (64.7)	8 (57.1)
Household income				
<\$10,000	0 (0)	13 (15.9)	1 (5.9)	2 (14.3)
\$10,000 – 80,000	9 (75.0)	55 (67.1)	12 (70.6)	10 (71.4)
>\$80,000	3 (25.0)	10 (12.2)	3 (17.6)	1 (7.1)
Other stress in past 6 months	1 (8.3)	17 (20.7)	5 (29.4)	6 (42.9)

CI: Cochlear implant; HA: Hearing aid; NA: Not applicable

\* $P < 0.05$  (2-tailed)

functioning and academic functioning differed significantly among children with different hearing devices ( $P < 0.05$ ).

*Expert Panel Review*

After multiple rounds of review by the expert panel, 7 questions as shown in Table 2 were removed. These questions were removed primarily because of their focus on sign language. They are less relevant in Singapore compared to the United States, as only a small number of children with HI are attending a school in Singapore where the primary medium of instruction is sign language.

**Data Analysis**

*Exploratory Factor Analysis*

Exploratory factor analysis was conducted on the remaining 61 items after the imputation of missing data and item recoding. Each of the different non-graphical solution to the scree test yielded different number of factors to retain. The number of factors ranged from 1 to 14 (Fig. 1). The suggested factor solutions were studied but none of them yielded any interpretable solution. A more thorough search for an interpretable solution was conducted for a 3- to 14-factor structure. The 1-factor structure was not included in the search as adopting a 1-factor structure would imply that the construct of caregiving is essentially one-dimensional. Given the wide range of sources for caregiving stress, the authors decided to search for a solution that is more than 1 factor. A 6-factor solution was eventually adopted as the most interpretable factor solution yielding the factors, “Expectation”, “Policy”, “Healthcare”, “Education”, “Support”, and “Adaption”. The 22 items with high cross-loadings were removed (Table 3). This solution however had a factor, “Expectation”, with only 2 items (Question 42 and 40) left after the removal. A decision was then made to move these 2 items to the next factor on which it loaded heaviest on (to “Policy” and “Adaption” respectively). This was done as factors with small number of items would be hard to interpret.<sup>22</sup> This resulted in a 5-factor solution.

Table 2. Questions Removed from Original 68-item PHICE Questionnaire due to Reduced Focus on Signing Requirements in Singapore

02	Child care provider/schools/teachers/out-of-home caregiver’s lack of signing skills.
22	Lack of interpreters for child.
25	My lack of signing skills.
36	My child’s lack of signing skills.
47	Healthcare provider’s lack of signing skills.
58	Immediate family and relative’s lack of signing skills.
67	Lack of a large deaf community.

PHICE: Paediatric hearing impairment caregiver experience

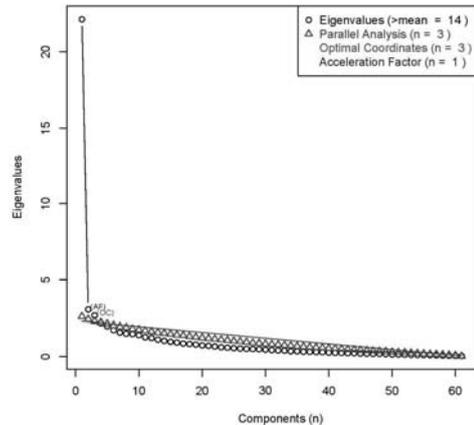


Fig. 1. Non-graphical solutions to the scree test. The number of factors suggested to retain is 14, 3, 3, and 1 by eigenvalues, parallel analysis, optimal coordinates, and acceleration factor respectively.

Table 3. Items in the Original PHICE with High Cross-Loadings

Items*		
50	(F)	Costly medical equipment and expenses.
37	(C)	Difficulty in communicating with my child.
57	(SO)	Problems discussing sexual issues with my child.
65	(H)	Worries about success of my child’s therapy or rehabilitation.
60	(EQ)	Caring for the hearing aid or implant.
68	(SO)	Seeing my child frustrated because of his/her hearing loss.
34	(SU)	Lack of childcare or babysitters for child.
51	(EM)	Having no time for myself.
18	(EM)	Not being able to attend to the needs of other family members.
52	(EM)	Overwhelmed by information on caring for a child with hearing impairment.
63	(H)	Worries about risks associated with medical treatment (e.g., surgery, hearing equipment).
14	(C)	Distinguishing between behavior and communicating problems.
64	(H)	Knowing that my child was diagnosed with hearing impairment late.
21	(SU)	Worries about deaf community’s perceptions of my decisions for my child.
55	(SU)	Inadequate support or understanding from spouse or partner.
17	(EM)	Worries about not doing enough for my child.
24	(SO)	Worries about my child’s safety.
30	(EM)	Feeling uncertain about disciplining my child.
31	(H)	Traveling to medical appointments.
61	(F)	Costly daily aids like vibrating alarms and teletypewriter (TTY) services.
06	(EM)	Having difficulties accepting that my child is hearing impaired.
19	(H)	Worries if my child is getting good medical care.

PHICE: Paediatric hearing impairment caregiver experience

\*The original factors in which the items below are denoted in parenthesis where C: Communication; ED: Education; EM: Emotional; EQ: Equipment; F: Finance; H: Health; SO: Social; SU: Support.

*Adjustments of Factor Solution*

Further changes were made to the 5-factor solution by the expert panel. Six questions assigned by the analysis software to certain factors were reassigned to other factors as shown in Table 4. This was done to ensure congruence between the meaning of the factors and the questions, and to improve interpretability of the factors. Three questions that were removed due to high cross-loadings were reintroduced by the expert panel as these questions were useful in identifying important factors that could negatively impact the rehabilitation outcome, and for which psychological counselling or financial help would be important (Table 4). They were grouped under existing factors based on their content after examining the change in model fit statistics as presented in the subsequent portions. Table 5 shows the actual 42 items of the modified PHICE, grouped under the 5 factors which represent the 5 categories of concerns contributing to caregiver stress for children with HI.

*Confirmatory Factor Analysis*

CFA was conducted on the original 8-factor model, the-5 factor model suggested in the exploratory factor analysis and the modified 5-factor model. Table 6 lists the various goodness-of-fit indices proposed by Hu et al.<sup>23</sup> From the various indices, we can see that the original 5-factor solution is a superior fit for the data. The changes made to the 5-factor model increased the levels of misfits as indicated by the

Table 4. Adjustment to Questions

Question	From	To
09 Feeling that healthcare providers do not listen to me.	Adaptation	Policy
35 Worries about my child’s ability to make friends.	Education	Policy
62 Relocation to be near resources that meet my child’s special needs.	Education	Policy
03 Working together with education professionals.	Healthcare	Policy
44 Understanding the laws related to hearing impairment.	Healthcare	Policy
42 Keeping large number of medical appointments.	Policy	Policy
06* Having difficulties accepting that my child is hearing impaired.	–	Policy
21* Worries about the deaf community’s perceptions of my decisions for my child.	–	Policy
50* Costly medical equipment and expenses.	–	Policy

\*Questions which were removed after exploratory factor analysis were reintroduced after reviews by the expert panel.

Table 5. Five-factor Solution Resulting in the Modified 42-item PHICE After Removal of Items with High Cross-loadings\*

Factor	Question Number and Question in Original PHICE
Policy	10 Inadequate support or understanding from an employer.
	28 Inadequate insurance coverage for treatment of hearing impairment.
	33 Not able to take time off from work to tend to child’s needs.
	39 Problems dealing with insurance company.
	44 Understanding the laws related to hearing impairment.
Healthcare	09 Feeling that healthcare providers do not listen to me.
	20 Working together with doctors.
	32 Feeling confused about medical information.
	42 Keeping large number of medical appointments.
	43 Working with the nursing or rehabilitation team.
	45 Difficulty getting information about hearing impairment or rehabilitation.
	50 Costly medical equipment and expenses.
Education	53 Difficulty getting medical and rehabilitation care.
	03 Working together with education professionals.
	27 Worries about decisions I have made for my child’s education.
	38 Child’s behavior in school.
	48 Child’s academic achievement in school.
	49 Lack of educational opportunities for my child.
Support	59 Child’s reading ability.
	15 Obtaining special learning materials for my child (e.g. books, captioned videos).
	21 Worries about the deaf community’s perceptions of my decisions for my child.
	23 Worries about others taking advantage of my child.
	26 Worries about choosing the best form of communication for child (oral, sign, total).
	29 Feeling partly responsible for my child’s hearing impairment.
	35 Worries about my child’s ability to make friends.
	41 Changes in my relationship with my partner or spouse.
	46 Worries about how my child fits into the hearing community.
	54 Worries about whether my child should have a hearing aid, cochlear implant, or no aid.
	56 Lack of support network of parents facing similar problems.
62 Relocation to be near resources that meet my child’s special needs.	
66 Inadequate support or understanding from friends and relatives.	

Table 5. Five-factor Solution Resulting in the Modified 42-item PHICE After Removal of Items with High Cross-loadings\* (Con't)

Factor	Question Number and Question in Original PHICE
Adaption	01 Child has temper tantrums related to hearing loss.
	04 Worries about my child losing or damaging his/her equipment.
	05 Being unable to go to work.
	06 Having difficulties accepting that my child is hearing impaired.
	07 Hearing aids or cochlear implants not meeting expectations.
	08 Delayed cochlear implantation.
	11 Child uses hearing loss as an excuse to behave badly.
	12 Feeling uncertain about my child's future.
	13 Sound of child's voice is irritating, loud or shrill.
	16 Equipment interfering with child's activities.
	40 Tired due to caring for my child with hearing impairment.

PHICE: Paediatric hearing impairment caregiver experience

\*In the shortened PHICE to be administered to caregivers, questions will not be grouped according to the 5-factor categories, so that caregivers would not know what issue is being assessed.

indices. Furthermore, the change between the original and the modified 5-factor model is deemed to be minimal. However, this is a trade-off that has to be made to improve the interpretability. The CFA suggests that after refactoring and reducing the number of items, the new factor structure is able to better explain the underlying phenomenon as expressed by the data.

#### Internal Consistency

Cronbach's  $\alpha$  values for the original and the modified 5-factor solution are presented in Table 7. All subscales had an  $\alpha$  value of more than 0.7 suggesting good internal consistency.<sup>24</sup> The change from the original 5-factor solution to the modified 5-factor solution is also minimal.

#### Questionnaire Results

The modified and shortened 42-item PHICE questionnaire results are shown in Table 8. While caregivers of children with no aids reported higher stress in the area of healthcare, caregivers whose children were aided with hearing devices reported higher stress in the areas of education and adaption. Caregivers of children aided with both CI and HA (bimodal aids in different ears) reported the highest levels of stress (low to moderate stress) over all 5 areas, followed by those of children aided with HA and children aided with CI ( $P$

$<0.05$ ). Caregivers of children with no aids reported the lowest levels of stress (no to very low stress).

#### Discussion

A total of 26 items have been removed from the original PHICE questionnaire and the factor structure has been changed. The 8-factor structure comprising "Communication", "Emotional Well-Being", "Equipment", "Financial", "Social", "Education", "Healthcare" and "Support" has been reduced to a 5-factor structure comprising "Policy", "Adaptation", "Education", "Healthcare" and "Support". The shortened PHICE questionnaire for our Singapore context is a 42-item instrument that can be completed in about 15 minutes. It is structurally valid and internally consistent as suggested by the goodness-of-fit indices and Cronbach's  $\alpha$  values.

#### Overlapping and Non-overlapping Factors

Given the adjustment of reassignment and reintroduction, some may worry that that the new structure could be an artefact of factor analysis and may not be meaningful in clinical usage. We thus discuss the overlapping and non-overlapping factors and explore the qualitative changes in the adjustment.

The 3 overlapping factors are shown in Table 9. The table was formulated after items were removed from the old factor structure and adjustments were made to the new factor structure. This allows for a fairer comparison of the changes made to the new factor structure. The number of shared items varies between 3 and 6 items suggesting that qualitatively, the factors share some similarity.

Both the healthcare and education subscales have more than half of the items in the new factors belonging to the old factor. This implies that these 2 subscales have changed little qualitatively. The items removed from and new items added to these 2 subscales were most likely due to the probable attribution to 1 or more of the subscales at the inception of the questionnaire. Factor analysis in this instance has helped to clarify under which subscale the items would more appropriately belong to. Furthermore, the new items are coherent with the implied meaning of the subscale.

The support subscale expanded from the original 6 items to the current 12 items. The original support subscale consisted of items that suggest the need of support for caregivers such as "Q56: Lack of support network of parents facing similar problems." The new support subscale contains items that pertain to the need of support for the child with HI such as "Q15: Obtaining special learning materials for my child (e.g. books, captioned videos)." A closer look at the various items under the new subscale reveals this difference. This

suggests that support in the context of caregiver stress may be homogenous, whether they are pertaining to the needs of caregiver or to the needs of the child with HI.

The other 5 non-overlapping subscales from the old factor structure have been regrouped into 2 subscales. The reassignments of the subscales have helped to better define the meaning of each subscale by the new composition of the items, and are supported by the confirmatory analysis.

#### Modified PHICE Questionnaire for Singapore

Results from the current study indicate that caregivers of children aided with different hearing devices experience different areas and levels of stress. Caregivers of children with no hearing aids worried more about “Healthcare” issues while caregivers of children with HA or CI had more concerns about “Education” and “Adaption” issues. Caregivers of children with HI with hearing devices reported significantly higher stress (stress score range, 3.39 to 4.14) than those of children with no hearing devices (score of 2.45).

This likely results from children with more severe HI naturally needing hearing devices more, as shown in Table 1. With more severe HI, the impact on education and academic achievements is more significant, even with hearing devices. Caregivers worry about their child’s educational options, progress in school, and working with the teachers (Table 5). With more severe HI, the impact on the child’s adaption is also more significant. For example, there would be more concerns regarding the child’s future options, worries that the hearing devices may interfere with the child’s activities and issues on regulating expectations about the hearing devices. The caregiver themselves have adaption concerns, like feeling tired while caring for the child, unsure of how to discipline the child, and being unable to go to work.

As children with HI without HA usually have less severe HI, the caregiver stress in the areas of “Education” and “Adaption” would correspondingly be reduced. This would allow other concerns like “Healthcare” to surface. They may feel that healthcare workers are not paying as much attention to them, as they do not need as many clinic visits

Table 6. Goodness-of-fit Indices

	8-factor Solution	5-factor Solution I*	5-factor Solution II†
Root mean square error of approximation (RMSEA)	0.087	0.068	0.074
Root mean square residual (RMR)	0.353	0.331	0.343
Standardised RMR (SRMR)	0.081	0.076	0.081
Normed fit index (NFI)	0.883	0.893	0.885
Incremental fit index (IFI)	0.937	0.949	0.944
Comparative fit index (CFI)	0.937	0.948	0.943

\*Refers to the factor solution before reassignment and reintroduction of items.

†Refers to after modifications to 5-factor solution I.

Table 7. Internal Consistency of PHICE (Cronbach’s  $\alpha$ )

Factor	5-factor Solution I*	5-factor Solution II†
Policy	0.770	0.737
Healthcare	0.862	0.854
Education	0.877	0.841
Support	0.875	0.890
Adaptation	0.875	0.873

PHICE: Paediatric hearing impairment caregiver experience

\*Refers to the factor solution before reassignment and reintroduction of items.

†Refers to after modifications to 5-factor solution I.

Table 8. Modified PHICE Scores of Caregivers of Children Aided with Different Hearing Devices

Subscale (factor)	Type of Hearing Devices				Average
	No Aid	HA	CI + HA	CI	
Policy	2.35	3.08	3.72	2.79	3.06
Healthcare*	2.71	3.63	4.10	3.00	3.54
Education*	2.40	4.34	4.35	3.95	4.11
Support*	2.53	3.86	3.89	3.50	3.70
Adaption*	2.25	3.86	4.62	3.70	3.79
PHICE*	2.45	3.76	4.14	3.39	3.64

CI: Cochlear implant; HA: Hearing aid; PHICE: Paediatric hearing impairment caregiver experience

\* $P < 0.05$

Interpretation of questionnaire scores: 0 = Not applicable, 1 = No stress, 2 = Very low stress, 3 = Low stress, 4 = Moderate stress, 5 = High stress, 6 = Very high stress, 7 = Extremely high stress.

Table 9. Overlapping Factors and Number of Shared Items

Factors	No. of Items		No. of Shared Items
	Old	New	
Support	7	12	3
Healthcare	9	8	6
Education	7	6	6

without use of the hearing devices. They may not be given as much medical information and support indirectly. For example, those with significant HI in one ear and normal hearing in the other ear may be deemed by many healthcare professionals to not need any help. However, they may have difficulty hearing in background noise situations like in classrooms; or if they are seated with the poorer hearing ear directed towards their teachers. Increasingly, the scientific literature supports the rehabilitation of even unilateral HI.

The degree of HI, social functioning and academic functioning differed significantly among children without and with different hearing devices ( $P < 0.05$ ). Interestingly, the group of caregivers who reported the highest levels of stress was not those with children who had the most severe/profound HI in both ears requiring CI, but it was the group of caregivers with children aided with both a HA and CI due to less severe HI in one of the ears. A closer look at Table 1 revealed that the second group of children also had a longer duration before diagnosis of HI was made (average age of 29 months, compared to the average age of 15 months for children with CI). The later diagnosis will result in poorer social functioning and poorer academic functioning for the child, which in turn will contribute to increased caregiver stress (Table 1).

#### *Utility of the Modified PHICE Questionnaire*

The modified PHICE questionnaire has increased relevance and will improve uptake of use in our Singapore population. It is a validated instrument which can be quickly administered with ease to caregivers who visit the clinics with their children. Identifying the factors and specific issues that cause the greatest stress to caregivers allows the healthcare team, teachers, other family members, caregivers, counsellors and social workers to help to mitigate the stressors for the caregiver. Reducing the stress for the caregivers can improve the downstream functioning outcomes for the child across audiological, educational and social function domains. The instrument can also be applied to longitudinal research studies to determine the impact of and effectiveness of reduction of various areas of stress for specific caregiver groups. We hope to have other healthcare groups adopt this questionnaire if it is relevant to their population, so that the modified questionnaire can

be validated in different populations of patients in other countries. It is very possible too that caregivers in Asia have concerns and stressors that are significantly differently from caregivers in the West, and this tool can be used to compare across different regions in Asia. Details of the various steps involved in validating the instrument have been documented to allow a conduct of a similar study to provide evidence for the validity of the instrument in the context of other populations where this could be relevant.

#### **Limitations**

Seven questions from the original PHICE were removed primarily because of their focus on sign language. They are less relevant in Singapore compared to the United States, as only a small number of children with HI are attending schools in Singapore where the primary medium of instruction is sign language. With the Singapore Universal Hearing Screening Programme having been established in restructured hospitals in Singapore since 2001, and with good uptake in the private hospitals all over Singapore too, diagnosis of newborn HI within 3 to 6 months of birth is the norm here, and hearing rehabilitation is started early with HA, CI, and speech and language therapy where appropriate. With increasing awareness of the importance of good hearing amongst the public, education and healthcare teams (teachers, paediatricians, child development specialists, speech and language therapists, audiologists and otolaryngologists), there is also now less delay in the diagnosis of HI in children, allowing good hearing and learning outcomes with early intervention.

As a result, sign language use as the sole or main form of communication for children with HI is decreasing in Singapore. Most of our children with HI are able to join mainstream schools, or schools with combined aural and oral communication, complemented by some signing only if needed. There will be a small subset of children with HI who still sign—mainly those with concomitant health issues like other cognitive, neurological, major system disorders, or the minority of families who prefer that the child only signs. For populations that do have extensive use of sign language, the results from the use of our modified instrument should be interpreted with caution as we are unsure of the dynamics of interaction of sign language with the various domains of caregiving.

#### **Conclusion**

The original 68-item PHICE questionnaire has been shortened to a 42-item PHICE and reorganised in 5 subscales from the original 8 subscales. The resulting instrument is structurally valid and internally consistent, and is a useful tool to identify factors that can negatively impact rehabilitation outcome for HI in Singapore.

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