DOI: https://doi.org/10.54393/pjhs.v5i12.2167

PAKISTAN JOURNAL OF HEALTH SCIENCES
(LAHORE)
https://thejas.com.pk/index.php/pjhs
ISSN (P): 2790-9352, (E): 2790-9344
Volume 5, Issue 12 (December 2024)

Original Article

OPEN ACCESS

Tool Development for Parental Reviews of Cochlear Implanted Children in Urdu

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ARTICLE INFO

Keywords:
Cochlear Implantation, Congenital Deaf, Content Validity Index, Hearing Loss

How to Cite:
Shahid, R., Mubeen, R., Saqulain, G., & Awan, W. A. (2024). Tool Development for Parental Reviews of Cochlear Implanted Children in Urdu: Tool for Parental Reviews of Cochlear Implants. Pakistan Journal of Health Sciences, 5(12), 144-150. https://doi.org/10.54393/pjhs.v5i12.2167

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Received date: 28th August, 2024
Accepted date: 11th December, 2024
Published date: 31st December, 2024

ABSTRACT

The treatment of profound hearing loss and the adjustment of a child after this is a critical task for parents. Presently, cochlear implantation is the most common and effective treatment for profound hearing loss. However, navigating the decision-making process can be overwhelming for families. Currently, there is no standardized tool available in Urdu to help parents before taking the decision of cochlear implantation. **Objective:** To develop a tool to assess parental reviews of cochlear-implanted children in Urdu. **Methods:** This descriptive research conducted at Riphah International University (Sept. 2020-February 2021) utilized a sample of 20 parents of cochlear implanted children, aged 6 to 15 5 years. Parents included either gender aged 29 to 59 years. A semi-structured questionnaire was developed using interviews and existing literature. Themes from interviews and existing literature were used to develop items. Content validity was assessed by 5 expert speech and language pathologists. For the meaningfulness of each item, a cognitive debriefing interview was conducted with the parents. Each item was reviewed and modified as per suggestion and pre-tested. **Results:** A 92-item tool was developed with 07 subsections related to i) Decision of Cochlear Implantation, ii) Process of Cochlear Implantation, iii) Effects of Cochlear Implantation, iv) General Functioning of Child, v) Self-Reliance and QoL, vi) Education of Child and vii Communication. The tool revealed good reliability and content validity SCVI=0.94. **Conclusion:** The developed 92-item Parental Reviews of Cochlear-Implanted Children in Urdu (PRCIC-U) tool is a reliable and valid tool review of different stages of the cochlear implantation procedure for the Urdu-speaking population.

INTRODUCTION

Cochlear implantation is a surgical procedure of implantation of a neuroprosthetic hearing device that improves the sense of sound [1]. It is possible for the deaf person to understand speech and improve the sensitivity of sound [2]. Studies indicate that children implanted by 12 months of age are more likely to achieve education levels necessitating implantation before the age of 4 years in the case of congenital hearing loss [3, 4]. Literature suggests that approximately five percent of the world population (around 32 million adults and 34 children and adolescents) are hearing impaired. The degree of their hearing loss is moderate to severe, which is 40 dB for the good hearing ear of adults and 30 dB for the good hearing ear of children [5], with those in underdeveloped countries being most affected [6]. The benefits of implantation can also be measured in social terms, such as how the implantation helps in decreasing the educational cost and an aware life in the long run [7]. Literature reveals tools that may assist or influence the parental decision of cochlear implantation [8]. The data that parents give in the form of their reviews and experiences can be beneficial for the professional teams of implantation of the concerned parents and also for clinical usage [9]. However, no such tool in Urdu language exists. In academic achievement, it is significant that deaf children who have been implanted show considerably better results [10].

The vital impact of cochlear implantation is that it gave positive outcomes when the implanted child is grown up

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and able to go for employment, the same as the other of his peer groups.

METHODS

To develop a tool to assess parental reviews of cochlear-implanted children in Urdu (PRCIC-U), the current study utilized a descriptive research design with convenient sampling. The study was conducted at Riphah College of Rehabilitation Sciences, Riphah International University, Islamabad, over 6 months from 1st September 2020 to 28th February 2021. This study was initiated after obtaining ethical approval of the study from the Research Ethical Committee of Riphah International University vide Reference no. Riphah/RCRAHS/ISB/REC/00801 and informed consent of the parents of children. The confidentiality of participants was preserved. Though, convenience sampling can result in bias in research like selection and sampling bias, however since a special category of parents had to be selected carefully to obtain their ideas of their special experience. Hence using convenience sampling, the study recruited a sample of N=20 parents of cochlear-implanted children of Bahria Special Children College, Islamabad for pilot testing. The sample included both mothers and fathers, aged 29 to 59 years of whom 08 were permanent residents of the twin city of Islamabad and Rawalpindi while the remaining 12 were temporary residents. Only parents of children having experienced the procedure of cochlear implantation of their respective child with a child's age range 6-15 years and both genders were included. Parents of children having associated syndrome along with hearing impairment were excluded from the study. An inform consent was taken from the parents of children below 10 years of age, and children above the age of 10 after obtaining permission from the involved institution. Sample of Expert SLPs include n=5 SLPs of female gender and any age group with minimum PGD in speech language pathology and at least 5 years experience(table 1)

A detailed literature search was conducted to find existing tools and research articles related to parental review of cochlear implants. Semi-structured questions were used to ask parents about their experiences and problems faced by them during and after cochlear implant surgery. A list of items (95 questions) was generated by reviewing interviews and existing literature. The tool was categorized into different subparts of the cochlear implant procedure. The responses were calculated through a Likert Scale including 1= Strongly Agree, 2= Agree, 3= Neither agree nor disagree, 4= Disagree, 5=Strongly Disagree. The tool was developed by following the following protocols(figure 1).

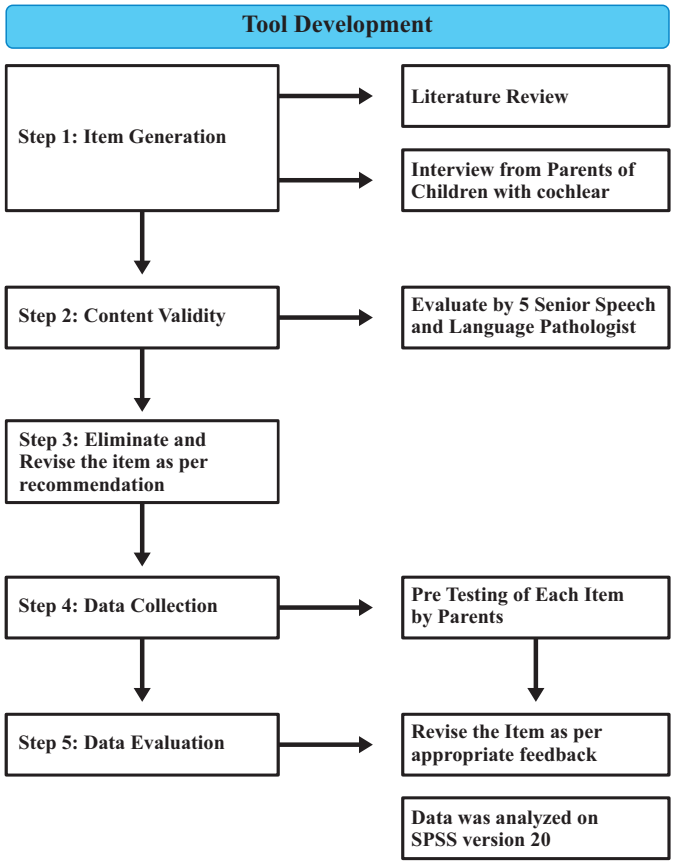

Figure 1: Consolidated Standards of Reporting Trials

Step 1: Generation of Items: Both inductive and deductive methods were used for generation of 95 item. Themes from interviews with parents and existing literature and existing scales on Parental reviews and experiences of children with Cochlear Implantation were used to develop items. Step 2: Content Validity: Assessed by 5 expert senior SLPs. The validity of content was also checked by the reviews and suggestions of five parents of cochlear-implanted children. Each item was reviewed and changed according to the suggestions of experts. Each item was rated by 5-experts on 4-point rating scale. Out of which the relevant rating was 3 or 4 which was scored as 5 and the non-relevant rating was 1 or 2 which was scored as 0. Content validity index I-CVI for items was calculated by the respective formula that expert in agreement divided by the number of experts for each item. Such items for which the result of I-CVI was less than 0.8, were considered to be revised according to expert advice. For the item that showed the I-CVI result 0, such an item was eliminated from the questionnaire as per expert opinion leaving behind 92 items. Step 3: Pre-testing of items: To check and ensure the meaningfulness of each item, a cognitive debriefing interview was conducted with the parents. Each item was reviewed and modified as per suggestion. Data analysis was performed using Statistical Package for Social Sciences (SPSS) version 20. Descriptive statistics was run

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to calculate the frequencies and percentages for demographics. The content validity index for items and the scale of the developed tool was also calculated.

RESULTS

The sample (N=20) of the current study revealed a mean age of 42.9 ± 7.67 years with the majority being females 15 (75%) and housewives 11 (55%) (Table 1).

Table 1: Demographic Characteristics of Sample

Variables	Group	N (%)
Sample of Parents (n=20)		
Gender	Male	5 (25%)
	Female	15 (75%)
Occupation	House Wife	11 (55%)
	Government Job	5 (25%)
	Business Personal	4 (20%)
Total		20 (100%)
Sample of Expert SLPs (n=5)		
S. No.	**Qualification**	**Experience**
1	MS (SLP)	5 Years
2	PhD	8 Years
3	PGD (SLP)	7 Years
4	MS (SLP)	6 Years
5	MS (SLP)	7 Years

Results revealed 92 items of different sections of the cochlear implant procedure. Initially, 95 items were generated. Seven sub-sections labeled as A to G were arranged to distribute all the items according to their respective sections. Each of these items was rated by 5 expert judges on 4-point rating scale. Out of which the relevant rating was 3 or 4 which was scored as 5 and the non-relevant rating was 1 or 2 which was scored as 0 (Table 2).

Table 2: Responses of Experts for Content Validity Assessment

Items Related To	Items	Experts in Agreement
A) Decision of Cochlear Implantation	1	5
	2	5
	3	5
	4	5
	5	5
	6	5
	7	5
	8	5
	9	5
	10	5
	11	5
	12	5
	13	5
	14	0
B) Process Of Cochlear Implantation	1	0
	2	5
	3	4
	4	5
	5	5
	6	5
	7	4
	8	5
	9	5
	10	5
	11	4
	12	5
	13	5
	14	5
	15	4
	16	5
	17	5
	18	5
	19	1
	20	5
	21	5
	22	5
	23	5
	24	5
C) Side Effects Of Cochlear Implantation	1	5
	2	5
	3	5
	4	5
	5	5
	6	1
	7	5
	8	5
	9	5
	10	5
	11	5
	12	5
D) General Functioning of Child	1	5
	2	5
	3	5
	4	5
	5	5
	6	5
	7	5
	8	5
E) Quality of Life	1	5
	2	5
	3	5
	4	5
	5	4
	6	5
	7	4
	8	4
	9	5

DOI: https://doi.org/10.54393/pjhs.v5i12.2167

	10	5
	11	5
	12	2
	13	0
	14	4
F) Education of Child	1	5
	2	5
	3	5
	4	5
	5	5
	6	5
	7	5
	8	5
	9	5
	10	5
	11	0
	12	5
G) Communication	1	5
	2	5
	3	1
	4	5
	5	5
	6	5
	7	5
	8	5
	9	5
	10	5
	11	5

Content validity index I-CVI for items was calculated by the respective formula that expert in agreement divided by the number of experts for each item. Such items for which the result of I-CVI was less than 0.8, was considered to be revised according to expert advice. For the item that showed the I-CVI result 0, such item was eliminated from the questionnaire as per expert opinion (Table 3).

Table 3: Content Validity of Tool Items

Sections	Items No.	Relevant (Rating 3 or 4)	Not-relevant (Rating 1 or 2)	I-CVI	Interpretation
A) Decision of Cochlear Implantation	1 to 14	5	0	1	Appropriate
B) Process of Cochlear Implantation	1	0	5	0	Eliminated
	19	1	4	0.2	Needs Revision
	2-18, 20-24	5	0	1	Appropriate
C) Effects of Cochlear implantation	1-5, 7-12	5	0	1	Appropriate
	6	1	4	0.2	Needs Revision
D) General Functioning of Child	1 to 8	5	0	1	Appropriate
E) Self-Reliance and QoL	1 to 11	5	0	1	Appropriate
	5,7,8,14	4	1	0.8	Appropriate
	12	2	3	0.4	Needs Revision
	13	0	5	0	Eliminated
F) Education of Child	1-10,12	5	0	1	Appropriate
	11	0	5	0	Eliminated
G) Communication	1-2,4-11	5	0	1	Appropriate
	3	1	4	0.2	Needs Revision

As a result of I-CVI, all 14 items of section A were considered to be appropriate, from section B out of 24 items, item 19: کا کلئیر امپلانٹ کے عمل حکومتی میسر ہونا ہماری مشکل آسان کر سکتا تھا was revised and 1 items was suggested to be eliminated. From section C out of 12 items, item 6: شروع میں ہماری توقعات یہ بھی تھی کہ ہمارا بچی فوری طور پر ساری آوازوں سے آشنا ہو جائے گا was revised, in section D all 8 items were considered to be appropriate, in section E out of 14 items item 12: کا کلئیر امپلانٹ سے پہلے اس میں اعتماد، تحفظ اور یقین کا فقدان تھا وہ امپلانٹیشن سے پہلے ہم پر بہت انحصار :13 was revised and item مین اسٹریم :11 was eliminated, from section F item اسکولوں میں اسپیچ تھراپیسٹ کا ہونا ضروری ہے تا کہ امپلانٹیشن والے بچے اٹریم میں تعلیم حاصل کر سکیں اور اسپیچ تھراپیسٹ سے فائدہ اٹھا سکیں was eliminated out of 12, and from section G out of 11 items item 3 اس کا بولنے کا معیار تشویش کا باعث تھا was revised. A total of 3 items were eliminated and 4 items were considered to be revised according to expert advice of all judges. Hence 92 items are considered to be appropriate after elimination and revision with SCVI of 0.93. Table 4 showed the frequencies of reliability of items. Responses for each item were checked in Yes and No by debriefing interviews with parents. Yes, indicates that the item is reliable, no indicates that the item is not reliable. Only responses for important items are mentioned below with concerned statements (Table 4).

Table 4: Frequency of Reliability of Items checked by pilot testing by debriefing interview with parents

Variables	Categories	N (%)
اس بات کا فیصلہ کرنا کہ آیا ہمیں امپلانٹ کروانا چاہیے یا نہیں، یہ ایک سب سے بڑا مشکل مرحلہ تھا۔	Yes	20 (100%)
	No	0
امپلانٹ کروانا کس عمر میں فائدہ مند ہوگا اس بات نے ہمیں پریشان کیا۔	Yes	18 (90%)
	No	2 (10%)
ہمیں کاکلیئر امپلانٹیشن سے قبل، متعلقہ ماہرین تک رسائی نہ ملنے کے باعث پریشانی کا سامنا کرنا پڑا۔	Yes	19 (95%)
	No	1 (5%)
ہم دونوں میاں بیوی میں سے اگر کوئی بھی امپلانٹیشن کی مخالفت کرتا تو بچے پر اسکے منفی اثرات مرتب ہونے کا کلیئر امپلانٹیشن کا عمل والدین کے لئے تحفظات دینے والا عمل ہے۔	Yes	19 (95%)
	No	1 (5%)
امپلانٹ کرانے سے پہلے کسی دوسرے ایسے خاندان سے ملنا بہت مفید ہے جو۔	Yes	19 (95%)
	No	1 (5%)
کلیئر امپلانٹ کروانے کا تجربہ رکھتے ہوں۔	Yes	19 (95%)
	No	1 (5%)
مجھے اُمید ہے کہ امپلانٹ سینٹر ہمیں امپلانٹ کے بعد پیش آنے والی مشکل میں مدد کرے گا۔	Yes	19 (95%)
	No	1 (5%)
شروع میں ہماری توقعات یہ بھی تھی ہمارا بچہ اپنی امپلانٹیشن کے فوری بعد سننے کے ساتھ ساتھ بولنا بھی جاری کر دے گا۔	Yes	18 (90%)
	No	2 (10%)

DOI: https://doi.org/10.54393/pjhs.v5i12.2167

امپلانٹیشن کی وجہ سے اسے دوسری طبعی مشکلات کا سامنا کرنا پڑا۔	Yes	17 (85%)
	No	3 (15%)
چونکہ اب یہ اپنے اردگرد کی آوازوں سے واقف ہے اس لیے میں اب اسکو کھیلنے دیتی ہوں۔	Yes	19 (95%)
	No	1 (5%)
امپلانٹیشن کے بعد بھی یہ مین اسٹریم اسکول کا مقابلہ کرنے سے قاصر ہے۔	Yes	19 (95%)
	No	1 (5%)
امپلانٹیشن سے قبل یہ سکول میں محض وقت گزار رہا تھا۔	Yes	19 (95%)
	No	1 (5%)

DISCUSSION

The decision for the Cochlear Implantation (CI) procedure is difficult and stressful for the parents [11]. Due to non-availability of tool to determine the parental view and experiences of children with cochlear implantation, this study aimed to develop a tool that can assess the parental views and experiences of children with a cochlear implantation because this can benefit many other parents who are going for their child's implantation. Inspired by the literature, a study conducted in the United Kingdom indicated that there was a need to assess parental views for future ease [12]. The currently developed tool was categorized into parts. Each part comprises steps of the implantation procedure and the pros and cons of implantation on a child's mental health, quality of life, and parental experiences. The initiative behind these items was taken from the literature and a few existing tools which indicated the importance of assessment of parental experiences [13]. The purpose of developing this tool in the Urdu language was to facilitate the Pakistani population and parents from all backgrounds. As Urdu is the national language of the majority of Pakistani people these items in Urdu would be easy and readable for all the parents who can read and understand Urdu language. Keeping in view that content validity of a new developed tool should be assessed since it is essential hence, the overall Content validity index (SCVI) was assessed and it was 0.93, which is appropriate to support the literature which is more than 0.8 [14-16]. In a study related to the development of a content-valid scale, the investigator evaluated the outcomes of the content validity of the scale [14]. Certain steps should be followed while developing a tool these steps include identification of the area that needs to be measured. This is done by reviewing already existing literature, scales, and interviews [15], as done in the current study. The study suggests protocols for checking the content validity of the developed tool [14]. in which the experts mark each item for relevancy, clarity, reliability, and ambiguity. According to the content validity of each part, most of the experts have given the score of 1, 0.93, and 0.91, which is appropriate to support the content validity according to the literature [14]. The items below 0.8 were revised, and the items which were indicated as 0, were eliminated from the questionnaire. In the current study, frequencies of parental feedback were evaluated on each item related to the cochlear implant decision. Many researchers suggested that the most stressful phase is to decide on implantation [3, 16], indicating the need to cater to stressors [17]. In this tool, items were developed regarding the complications and concerns of parents while deciding on a cochlear implantation. The frequencies of feedback indicate that the reliability of the decision of cochlear implantation is the most important concern of parents [18]. In Urdu PRCIC-U, the items related to financial burden were also added, since this is an important aspect of parents' concern [,]. Studies suggest that, in underdeveloped countries, the prevalence of hearing loss is a huge burden on the economy [4]. Items regarding the expense related to cochlear implantation provide very clear results that parents need financial consultancy before proceeding toward the implant which is the significance of this tool because in existing tools there were no items related to financial constraints. Financial aspects in developing countries like Pakistan need to be catered since this makes implantation difficult [21, 22]. Items related to education of children were generated after the theme that was extracted from the parental interviews. Many studies suggest that parents are worried about the post-surgery improvement and the quality and performance in the field of education were their great concern [7]. The results of parental feedback indicate that the education of a child is the second major concern of parents after cochlear implant surgery, though implanted children hear better in daily life [22]. Parents gave this feedback that the availability of this tool enabled them to take an interest in participating of this study. The results of debriefing interviews show the parental feedback regarding feasibility and quick understanding of items in Urdu. Parents also suggested a few items to be added to the tool in future research. Many parents report that they were worried about the limited resources in their city and from where they should avail the facility of cochlear implantation. In debriefing interviews, parents acknowledge the development of tools in their familiar language. This study can benefit the future research due to the fact that this tool can inform parents and caregivers what they should expect at different stages of the cochlear implantation process. This is very important since there is no such tool available in Urdu language in Pakistan. This tool is also very important for future research in the area.

CONCLUSIONS

The developed 92-item Parental Reviews of Cochlear-Implanted Children in Urdu (PRCIC-U) tool is a reliable and valid tool review of different stages of the cochlear implantation procedure, for Urdu speaking population. It is

DOI: https://doi.org/10.54393/pjhs.v5i12.2167

recommended that more items can be generated from the diverse population across the country. Secondly, it is also suggested that parental views should be analyzed across different cities to check the availability of the quality of resources in the country. Due to the Covid-19 pandemic, and traveling limitations small sample was utilized with generalizability limitations. Also, convenience sampling may result in research bias.

Authors Contribution

Conceptualization: RM
Methodology: RS
Formal analysis: RS
Writing, review and editing: GS, WAA

All authors have read and agreed to the published version of the manuscript

Conflicts of Interest

All the authors declare no conflict of interest.

Source of Funding

The author received no financial support for the research, authorship and/or publication of this article.

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