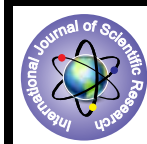


A Brief Overview of the Methodology in Developing A New Quality of Life Questionnaire For Children With Hearing Loss -The Impact of Hearing Loss on Children: IHL-C (Tamil)



Social Science

KEYWORDS :

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ABSTRACT

Determining health related Quality of life in children has become an area of increasing interest . A similar perspective is finding its application in field of the rehabilitation of differently abled. Consequently, health related Quality of Life tools is being utilised. . It is recognized that Quality of Life is fundamentally a holistic concept that goes beyond the health dimension. It has been suggested that it is impossible to differentiate what conditions or circumstances influence what aspect of one's life, and that Quality of Life is affected not only by the disability but also by the person's experiences. In this regard, an attempt is being made to develop and validate the new Quality Of Life Questionnaire for Children with Hearing Loss - The Impact of Hearing Loss on Children: IHL-C (Tamil). The paper will outline the process involved in developing the instrument. The resultant instrument will be multidimensional and will enable to provide better services for the children with hearing loss.

Summary

The new quality of life questionnaire will be addressing the varied aspects of quality of life from education through social integration to family relationships and general functioning. The content of the new scale will also reflect the areas of importance targeted by the various stake holders. In conclusion, impacts of hearing loss will be looked upon in different dimensions so as to ensure holistic outcome in the Habilitation and Rehabilitation of children with hearing loss.

INTRODUCTION

Habilitation (program designed to help children with congenital hearing loss to achieve highest potential) and rehabilitation (program designed to help children with adventitious hearing loss to restore the highest potential) is more than Individual Education Plans (IEP), learning and textbooks. Children need to develop competence to have positive physical, emotional and social experiences. The concept of World Health Organization (WHO) Quality of Life Group on health, that quality of life is concerned with the individual's perception of their position in life in the context of the cultural and value systems in which they live, and in relation to personal goals, expectation, standards and concerns above mere absence of the disease, can be extended to apply in the process of habilitation and rehabilitation of children with hearing loss. This represents an expanded view from traditional intervention programs that focus on the physical functioning i.e. skill attainment and developmental gains to overall physical, psychological and social well-being. The measures of quality of life can ensure the efficacy of the program and provide the impact of rehabilitation and habilitation program in child's life as well. Moreover, an instrument is not available to assess such outcomes among children with hearing loss in India. The primary aim was to develop a questionnaire to assess the impact of hearing loss for children; aged 8–18 years based on information from the children with hearing loss, and their support providers.

NEED OF THE STUDY

Studies concerning hearing impaired children have found that they present more behavioral and social problems than their normal hearing peers. However, there is currently no available quality of life assessment tool specifically available for children or adolescents with hearing loss. Through investigating what difficulties children and adolescents with hearing loss experience related to QOL categories, we will be able to generate a list of significant topics and create a quality of life questionnaire.

OBJECTIVES

- To develop an instrument to understand the needs of children with hearing loss to plan programs that enables the child to attain their fullest potential.

- To determine the psychometric properties of the instrument
- To provide a tool for the team working with children with hearing loss to identify areas where supplementary interventions are needed.

Methods

The content of the questionnaire will evolve out of literature review, expert review and focus group discussions with the key stake holders - service providers, parents, teachers, special educators, rehabilitation professionals, and children with diagnosed auditory problems (diagnosis based on ENT/Audiologist confirmed reports). The problem statements thus generated will be grouped under domains based on the semantic meaning and context. A questionnaire will then be developed based on the results of the analysis of the focus group discussions. The psychometric properties of the questionnaire will be validated for item reduction, acceptability, internal consistency of the items, test-retest reliability, content and construct validity, known group differences, convergent and discriminant ability and responsiveness. The final questionnaire will be administered to a sample of children with hearing loss pre and post intervention to confirm the ability of the instrument to measure changes over time.

Design

Questionnaire validation Research

Sample size

200 children in school going age with hearing loss (diagnosis based on ENT/Audiologist confirmed reports) of both genders will be recruited for the questionnaire research.

200 children with normal children studying in Integrated School whose one of the class mate is a child with hearing loss.

Process

Review of literature will precede focus group discussions. This is to identify the broad themes of the questionnaire and also to provide lead lines to develop discussions around the theme during the focus group discussions. They may include general functioning, adaptations, social aspects, psychological aspects, competence in communication among others. The broad theme identified will be indicative of the parameters that determine the impact of habilitation and rehabilitation process.

The focus group discussions will then follow. Focus groups will be held separately for each stakeholder with each focus group having 4-8 members. Each session will be tape recorded and transcribed. Thus, varied opinion statements of the children,

parents, special educators and service providers around the broad theme and any other missed out indicators and detail will be pooled in.

The transcriptions will be then converted into problem statements. The statements will be reviewed, merged to eliminate redundancy so as to come up with most plausible problem statements. These statements then take the question form. The questions are checked to see whether they reflect the intent of the problem statements and are segregated into major domains. This entire process brings out the first prototype of the questionnaire.

This prototype is then administered to the stakeholders to check whether the content reflects the intentions and actually measures what it has to measure (face validity). The questionnaire may undergo revision and is then administered to the children and tested for psychometric properties. The questionnaire may further be revised and reduced and its factor structure is then confirmed.

The final questionnaire will be administered to children before and after interventions to evaluate whether it is able to measure the outcomes after a specific time interval.

Statistical analysis

Item reduction will be done using methods in Classical test theory and the responsiveness of the items will be based on item response theory. The Test-retest reliability will be assessed

through Pearson/Spearman correlations. Content validity will be derived from focus group discussions and field testing. Internal consistency and structural validity will be determined through Cronbach α coefficient. Convergent validity will be established by exploring the association of scores with levels of auditory difficulty. Differences in score between the children with auditory challenge and typical children will show the "known group differences". Confirmatory Factor Analysis (CFA) and Structural Equation Modeling (SEM) techniques with AMOS software will be used to confirm the factor structure of the questionnaire. Effect size will be used to determine the magnitude of the differences after pre and post rehabilitation. The effect sizes will be calculated as mean difference in the Rasch calibrated scores divided by pooled standard deviation at baseline. Repeated measures ANOVA of the Rasch calibrated scores will also be used to determine the pre-post differences after adjusting for the influences of covariates like age and gender.

Data analyses will be carried out with SPSS statistical software, AMOS software for confirmatory factor analysis.

Outcome

The resultant is a valid and a reliable instrument - Quality of Life Questionnaire for Children with Hearing Loss -The Impact of Hearing Loss on Children: IHL-C (Tamil) to measure the outcomes of rehabilitation services for children with hearing loss. The scale should be able to identify areas for further supplemental intervention for children.

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