

Developing the Content of a New Quality of Life Questionnaire for Children with Hearing Loss

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ABSTRACT

Habilitation and rehabilitation call for a paradigm shift from the traditional intervention programmes which focus on physical functioning to programmes that include aspects of physical, psychological and social wellbeing.

Purpose: *To develop a quality of life instrument, using focus group discussions to assess the outcomes of interventions for school-going children with hearing loss.*

Methods: *Separate focus group discussions were held with children with hearing loss between 8 and 18 years of age, special educators and mothers. Focus group discussions were conducted separately for boys and girls. Each focus group had 8–10 participants. In-depth interviews were conducted with the heads of institutions and rehabilitation professionals. Fathers had to complete self-administered questionnaires. The focus group discussions were guided by topics and probes drawn from literature reviews, and were audio recorded, transcribed and analysed.*

Results: *Around 421 problem statements were classified under 7 themes: Educational implications; Social integration; Psycho-social wellbeing; Family relationships; Speech, language and communication; Leisure and recreation; and General functioning. Education and career aspirations were considered to be most important. The problem statements revealed that the primary focus of training was on improving academics. Integration and feeling comfortable with social situations were cited as limitations; as also, the preference for friendship with people of similar abilities. For the majority of children, leisure and recreation was limited to watching television. Parents and siblings were considered vital to their progress and achievements.*

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***Conclusions:** Multidimensional and varied perspectives of different stakeholders, especially family members, are necessary for a comprehensive analysis of the impact of hearing loss on the quality of life of school-going children.*

***Key words:** Disability, quality of life, deafness, rehabilitation, focus group discussion*

INTRODUCTION

The auditory sense is crucial for human beings to relate to their surroundings. Since it is essential to the development of verbal communication, any auditory impairment will have adverse consequences, particularly if it is present at birth or if it occurs during the early years. Mental development, as well as the child's acquisition of linguistic and speech skills, will be affected. It also causes far reaching impediments on social-emotional development, academic achievement, cognitive functioning and vocational opportunities (Rehabilitation Council of India - RCI, 2006). The impact extends beyond the affected individual to the family, and society at large.

In India, every year 25,000 children are born deaf. The state of Tamil Nadu has a high rate of prevalence at 428/100,000 persons when the National Average is 291/100,000 persons (AYJNIHH, 2013). To address the need, the Government of India has launched many programmes that emphasise screening for hearing loss in children, offering suitable assistive technology like hearing aids and cochlear implants, organising suitable educational services through special schools and inclusive education, reaching children in the rural pockets through Sarva Siksha Abiyan (SSA) - universal primary education - and developing manpower and resources. Over the years, society and professionals have become increasingly aware of the need for early identification and intervention, auditory training and speech training. Of late, with the growing focus on the concept of "Quality of Life", it has become imperative to mitigate the consequences of hearing loss through provision of overall physical, psychological and social wellbeing, looking at how the children are performing, not only audilogically but also in every sphere of life.

According to the concept of World Health Organisation (WHO) Quality of Life Group (1994) on health, quality of life is concerned with the individual's perception of his/her position in life in the context of his/her cultural and value systems, and in relation to personal goals, expectations, standards and concerns above mere absence of the disease. Quality of life includes not only wealth and

employment, but also the built environment, physical and mental health, education, recreation and leisure time, and social belonging (Gregory et al, 2009). In short, the key aspect of quality of life is life satisfaction (Polat, 2003). Allan Colver (2008) points out in his study that *“if we can broaden our clinical thinking beyond the biomedical dimensions of diseases to include participation ... we may help improve the quality of life and long term wellbeing of children with disability and young people along with their families”*. This represents an expanded view from traditional intervention programmes that focus on physical functioning, i.e., skill attainment and developmental gains, to overall physical, psychological and social wellbeing.

Quality of life for children is a holistic concept with many dimensions. The major elements of quality of life are child, family and the environment. Quality of life is an outcome of the interrelationship among these elements, inclusive of the opportunities and limitations each child has in his/her life reflected through the interaction of personal and environmental factors. The Quality of Life Research Unit, University of Toronto, has identified the major areas of life as Being, Belonging and Becoming – the 3 ‘Bs’. Being is how the child perceives self, how the child is seen and treated as part of the family, by others and the community. Belonging is how the child is understood by others, and is counted by the positive interactions the child has in his/her environment and how well he/she fits into the environment. Becoming is conceptualised as improving and maintaining the knowledge and skills so as to meet the expectations of the significant others (Renwick et al, 2003).

Based on this, an assumption can be made that mere possession of skills is not the only indication of a better quality of life. The better a child develops and utilises skills to fit into the environment, the better will be the quality of life. In short, quality of life determines the social situations achieved through psychological wellbeing, and vice versa.

Further, Wallander et al (2001) and King et al (2006) opined that a multi-dimensional quality of life construct can help parents, professionals and policy-makers to create a positive and stimulating environment for the child to experience maximum wellbeing. Parents are enabled to understand that the focus should not be on the child’s disability, and that attempts should be made to describe and understand the child’s life experiences. Professionals will have a better understanding of a child’s needs and goals, and can help one to consider the possible impact of a treatment recommendation on the child’s (and the family’s) quality of life. In

addition, these measures could be used to evaluate specific interventions. The results provide guidance to service providers in choosing measures based on their needs and purposes. As for policy-makers, quality of life is a global outcome that can be used across all ages and diagnostic conditions. Hence, the tool can be utilised to evaluate policies and programmes.

There are a number of paediatric quality of life tools available, but none have been designed to elicit the impact of hearing loss (Streufret, 2008). Most of them are designed for children with chronic health conditions, and the ones related to hearing concentrate on skill development. Moreover, none of the tools reflect the opinions and experiences of the population of concern - the focus groups – and instead rely upon the opinion of experts or caregivers (Balch & Mertens, 1999; Ronen et al, 2001). Proxy opinion is recognised as a serious limitation to accurate interpretation of quality of life (Fayers & Machin, 2000; Cochrane et al, 2008). Therefore, there is a need for a user-defined tool (Ronen et al, 2001) to describe and quantify the impact of hearing loss on children.

In this regard, it was decided to develop a quality of life questionnaire to study the impact of hearing loss on children between 8 and 18 years of age, based on information from them and their support providers. This article describes the method adopted to develop the content of a multidimensional quality of life instrument in Tamil language, to measure the outcomes of habilitation and rehabilitation services for school-going children with hearing loss in the age group of 8 – 18 years.

METHOD

A semi-structured data gathering method was adopted to develop the content of the questionnaire. Focus group discussions are particularly well-suited to identify and describe in-depth issues that are otherwise not well known. This qualitative research technique elicited the views, opinions, problems and beliefs of the participants. A discussion guide was developed, consisting of broad topics and probes to keep discussion centred on the topic while participants communicated their perceptions.

In-depth personal interviews were also employed. The questions for the interviews were taken from the discussion guide, as also from an informal self-administered questionnaire containing both close and open-ended questions.

Ethics Approval

The research study was approved by the Ethics Committee of the Research Department of Rehabilitation Science and Special Education, Holy Cross College (Autonomous), affiliated to Bharathidasan University, Tiruchirappalli, Tamil Nadu, where the first author is a PhD scholar. Initially, the proposed study was discussed with the heads of both the Special and Integrated schools and the Research Advisor (second author) of the Department of Rehabilitation and Special Education.

Study Sample

Participation in the study was voluntary. The purpose of the study was explained to the respondents before the interview and the focus group discussions, and their verbal consent was sought. Participants also gave permission for audio recording of focus group discussions and interviews.

The students who participated in the study were recruited from Dolours School for the Deaf, Tiruchirappalli, Tamil Nadu. From among 120 children, 10 boys and 8 girls were randomly selected on the basis of certain criteria.

The participants were 'children' as per Article 1 of the UN Convention for the Rights of the Child. Accordingly, every person below the age of 18 is considered a child, unless the laws of a particular country lower the legal age for adulthood. The participants, between 8 -18 years of age, had different degrees of bilateral hearing loss - ranging from mild to moderate and severe to profound. Students with cognitive, physical and other sensory problems were excluded. For the focus group discussions, only students who had sufficient speech intelligibility were included, as the inclusion of translators could alter the free flow of thought. The students were asked to wear hearing aids, and doubts were clarified through written communication. Discussions were conducted in the regional language (Tamil) with which the children were familiar. Apart from the students, other stakeholders included mothers, fathers, special educators, two heads of institutions and one rehabilitation professional. Mothers and fathers were connected with the school from which the students were chosen. Special educators were from the Dolours school and Ramana MahaRishi Vidhya Mandhir preparatory school for the deaf, Tiruchirappalli. The heads of these two institutions were interviewed. The rehabilitation professional was an Assistant Professor at the Research and Post Graduate Department of Rehabilitation Science and Special Education.

Discussion Guide - Topics and Probing Responses

Quality of life instrument is generally conceptualised as a multidimensional construct encompassing various domains. A review of literature enabled the identification of broad topics for the questionnaire and the documentation of probes to keep the discussions convergent on the themes. The probes acted as lead lines for the discussions. The researcher used open-ended questions and narrated true life experiences of other children to introduce the topics and prompts.

Table 1: Discussion Guide

| Topics | Examples of Probing Responses |
|--|--|
| Description of the hearing loss | <p>How does hearing loss affect your life in general?</p> <p>How do you think your hearing has affected you most in the things that you do?</p> |
| Impact of hearing problem on education and functioning at school | Describe the problems encountered in school |
| Impact of hearing problem on daily living activities | How do you think hearing loss affects your independence in daily living activities? |
| Impact of hearing problem on self | <p>How do you cope with the difficulties faced due to hearing loss?</p> <p>Are you concerned about wearing hearing aids in public?</p> <p>Does your hearing problem affect how others view or treat you? If so, how?</p> |
| Impact of hearing loss on the family and relationships | <p>Does your hearing problem affect the lives of your parents? If so, how?</p> <p>How have your siblings taken your hearing loss?</p> |
| Impact of hearing loss on social relations | How do you think your hearing loss has affected the way you get along with and mix with other people? |

The researcher changed the wording of the different probes in keeping with the participant groups. For example, the probe for the children –‘Are you concerned about wearing hearing aids in public?’ – would, for the special educators, be modified as - ‘Are the students concerned about wearing hearing aids in public?’ – and for the mothers as - ‘Is your child concerned about wearing hearing aids in public?’. The interview was conducted using the set of questions and probing responses from the discussion guide. The self-administered questionnaire for fathers was developed in the same way, and consisted of similar probes used for the mothers.

Focus Group Participation

Each focus group discussion was restricted to one type of participant only – students (children with hearing loss), mothers, or special educators. Separate focus group discussions were conducted for boys and girls since needs and situations could vary. Each group had 7 - 8 participants. The other focus group discussions which involved mothers and special educators had 8–10 participants per group. Both male and female teachers participated. The discussions with all the other stakeholders were also conducted in Tamil.

The discussion venue was comfortable and free from distractions. The participants and the researcher sat in a circle so that participants could face each other to talk spontaneously and hear the discussions clearly. Importance was given to addressing the participants by name, particularly when students were involved. To ensure effective participation, convenient timings were chosen for each group. The researcher explained the purpose of the study to each group, and the participants then introduced themselves and gave some background information. Students mentioned the class in which they were studying and whether they were day scholars or hostel residents, parents spoke about their children and teachers talked about the subjects and classes they handled. All participants were encouraged to speak up. The researcher used prompts to keep the discussion going. Each group’s discussion lasted around 60 – 90 minutes and was digitally recorded.

Other Techniques

The responses of fathers (8) of children with hearing loss were recorded via self-administered questionnaires. Semi-structured interviews were conducted with 2 institution heads and 1 rehabilitation professional. These interviews lasted for 30 – 45 minutes and were digitally recorded.

Table 2: Focus Groups and Interviews

| Participants | Participants | | | Data Collection Method | Number of Groups | Number of Participants per Group |
|--|--------------|-----------|-----------|--|------------------|----------------------------------|
| | Male | Female | Total | | | |
| Students | 10 | 8 | 18 | Focus Group | 2 | 8-10 |
| Mothers | --- | 10 | 10 | Focus Group | 2 | 5-8 |
| Special Educators | 3 | 8 | 11 | Focus Group | 2 | 5-7 |
| Fathers | 8 | --- | 8 | Self-administered informal Questionnaire | | |
| Institution Heads | 1 | 1 | 2 | Interview | | |
| Professor at the Institute of Rehabilitation Science | | 1 | 1 | Interview | | |
| Total | 22 | 28 | 50 | | | |

Development of the Content of the First Prototype of the Questionnaire

The audio recordings from the focus group discussions were transcribed and collated using Microsoft Office. The discussions elicited 421 problem statements. Statements that reflected similar underlying difficulties were grouped together, as for example the statements which described problems in communication – “strangers are not able to understand what I speak”, “strangers ask me to repeat again”, “I always need another person to help me speak with strangers”. Seven different perspectives were elicited; the statements were further analysed in keeping with the different participant groups. Transcribed problem statements were reviewed and merged in order to eliminate redundancy and enhance plausibility.

Table 3: Focus Groups-Ranked on the Basis of the Problem Statements frequency

| Rank | Focus Groups | Problem Statements Frequency | % of Total Statements |
|------|-------------------|------------------------------|-----------------------|
| 1 | Students | 100 | 23.75 |
| 2 | Special Educators | 94 | 22.3 |
| 3 | Parents | 85 | 20.1 |
| 4 | Institution Heads | 84 | 19.9 |
| 5 | Professor | 58 | 13.7 |
| | Total | 421 | |

It was perceived that the statements fit into 7 broad themes that were indicative of the parameters that determine the impact of the habilitation and rehabilitation process. These were:

- **Educational implications:** The problem statements that determined the extent to which hearing loss affected learning ability, classroom participation, academic performance and participation in co-curricular activities.
- **Social integration:** Statements that revealed the extent of acceptance of children, their socialising ability, and stigmatisation if any.
- **Psycho-social wellbeing:** Statements that showed the level of confidence and the emotional reactions to hearing loss, and self-perception.
- **Speech, language and communication:** Statements that specified the ability to communicate and participate in social situations.
- **Family relationships:** Statements that reflected the relationships with parents and siblings, and the atmosphere at home
- **Leisure and recreation:** Statements concerned with the activities that the children were exposed to during their leisure time.
- **General functioning:** Statements that determined whether hearing loss caused impediments in day-to-day activities.

Table 4: Domains - ranked by problem statements frequency

| Rank | Domains | Problem Statements Frequency | % of Problem Statements |
|------|------------------------------------|------------------------------|-------------------------|
| 1 | Educational implications | 96 | 25 |
| 2 | Psycho-social wellbeing | 81 | 21 |
| 3 | Family relationships | 73 | 19 |
| 4 | Social integration | 53 | 13.8 |
| 5 | Speech, language and communication | 50 | 13 |
| 6 | General functioning | 20 | 5.2 |
| 7 | Leisure and recreation | 11 | 2.8 |
| | Total | 384 | |

These statements then took the form of questions. Questions were checked to ascertain whether they reflected the intent of the problem statement, and were phrased to make them less ambiguous and more understandable. Also, they were

designed for multichotomous response – always, frequently, slightly, seldom and never. Within each domain, the questions were arranged sequentially. Thus, there emerged the first prototype of the questionnaire, containing a total of 220 questions.

RESULTS

Only 6 of the 7 planned focus group discussions were conducted. As it was difficult to arrange the discussion with the fathers, it was decided to send them self-administered questionnaires through the school, after obtaining permission. In addition, 3 individual in-depth interviews took place with experts in education for children.

Excerpts from the Focus Group Participation and the Interviews

Educational implications

All the stakeholders felt that visual presentation of the concepts and the core theme of the lessons were needed to aid comprehension. The children said that they were able to follow the regular curriculum through suitable adaptations. Whenever they were unable to understand concepts, children of all age groups preferred 'signing'. It was found that parents too played a vital role in developing their children's academic skills. They assisted their children during home assignments and in the learning process. Children felt that co-curricular activities were given equal importance. The professionals felt that limitations in linguistic skills and limited vocabulary affected children's academic achievement. The heads of institutions stated that teachers needed to be creative and meticulously plan the teaching concepts. Parents believed that children's academic achievements were higher in special schools as they received individual attention. Both boys and girls were not too worried about future careers and had already thought of the adjustments that would be required to pursue professions of their choice.

Social integration

In a social situation, the primary concern of the students was the fear of being misunderstood. This was the same for both boys and girls. Their hearing acquaintances were only parents, siblings and known people. Students revealed that they avoided wearing hearing aids outside school in order to prevent unnecessary stares and questions. Parents and professionals stated that younger

children were more interactive in social situations while the older ones tended to be socially withdrawn. Parents also contributed towards helping their children function independently – by creating an environment that was familiar and comprised of known people, and by choosing only positive acquaintances for their children.

Psycho-social wellbeing

Some children are self-motivated and their hearing loss is no impediment to independence, while some withdraw socially in new situations and among unknown people. Children said they felt embarrassed and annoyed when people became inquisitive about their hearing loss. Parents and professionals were of the opinion that schools concentrated more on education, speech training and language, and consequently ignored the psychological development of children.

Speech, language and communication

All parents wanted their children to speak and preferred the oral mode of communication. The teachers felt that articulation errors were more during the initial years but reduced with time, though very rarely did they disappear. The children felt that poor speech clarity hampered communication with others. Professionals stated that the children's deficient language skills tended to persist.

Family relationships

Family plays a leading role in motivating and promoting academic achievement, language development and social functioning. Parents expressed the view that the presence of a child with hearing impairment contributed to family stress. They were always concerned about the child's future - from education to career and marriage. Parents of both boys and girls held similar perceptions in this regard. For many of the students, siblings remained their best friends irrespective of the gender; and sibling relationship also showed few problems and conflicts.

Leisure and recreation

Both boys and girls complained that parents would not let them ride bikes or bicycles on the roads. All of them felt that wearing hearing aids during play was a nuisance. Though they were exposed to various activities at school, most children confined themselves to watching television for recreation. Very few had hobbies and parents tended to pay less attention to this aspect of their lives.

General functioning

Fearing for the safety of their children, parents agreed that they did impose restrictions on activities such as riding bicycles, bikes, visiting grocery stores, using public transport, and so on. The professionals felt that students required age-appropriate exposure to activities like sending mail by courier, obtaining money orders and so forth. Children were sensitive to noise in their surroundings, and complained of the sounds in marriage halls, buses, restaurants and other public places.

DISCUSSION AND CONCLUSION

The limitations imposed by hearing loss and its impact on quality of life, as narrated by the focus group participants, showed both similarities and differences with the findings of many earlier studies. The focus group discussions helped to identify several experiences and needs related to hearing loss. The results revealed multiple concerns among students with hearing loss and their parents. The professionals too had their own perceptions. The opinions of children have been complemented by the perspectives of adults who interacted with them and supported them on a daily basis.

If the information for content development had been provided solely by professionals, the resultant questionnaire would have been biased towards academic skills and specialist inputs. Similarly, if the students' perspective had been the only consideration, the scale would be tilted towards social/communication and coping mechanisms. Gathering information from different perspectives provided a broader range of issues from which items could be developed. However, as children would subsequently be expected to answer the questionnaire, the concepts and concerns raised by other stakeholders had to be considered and presented in a way that they could understand.

Despite elaborate preparation, the children with hearing loss experienced some difficulties during the focus group sessions. As the researcher was unfamiliar with their mode of communication, speech was difficult to understand. It took longer to communicate but this was essential to ensure mutual understanding. The children with mild and moderate hearing loss acted as interpreters throughout the discussions. When some children required written communication, the whole group had to wait until the content was written out on the chart and then respond to it. It is clear from the different experiences recorded at the discussions and the

interviews, that inputs from all stakeholders are required to obtain a balanced, holistic scale.

The content of the new quality of life questionnaire will address 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 stakeholders. In conclusion, the impact of hearing loss will be viewed from different dimensions so as to ensure holistic outcomes in the habilitation and rehabilitation of children with hearing loss.

The prototype of the questionnaire will be first administered to schoolgoing children in special and integrated settings, to check whether the content reflects the intentions and actually measures what it has to (face validity). After this the questionnaire may undergo reduction in the number of items, and will again be administered to the children and tested for psychometric properties. The result will be the long version and the brief version of The Impact of Hearing Loss on Children: IHL-C scale (Tamil). The scale should be capable of providing a multidimensional perspective of the impact of hearing loss among such children, and the results should serve as frame of reference to develop quality interventions for children with hearing loss.

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