

Quality of Life Measures Provided by the Glasgow Benefit Inventory among Cochlear Implant Users: Is this Quality of Evidence Adequate to Assess Outcomes?

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Abstract

The quality of evidence presently available for assessing the Quality of life (QoL) outcomes in Cochlear implant (CI) users, is not of high level and is variable between cohorts and across centres of the world. There are many generic hearing-related quality of life measures available for assessment of the outcomes with the Glasgow benefit inventory (GBI) being the most popular, but these do not address in particular the diverse cultural, ethnic, cognitive, behavioural and socio-economic spectrum among the implantees. Since such confounders may influence the scoring system of these validated QoL tools, it is imperative to systematically analyze the existent literature to understand the quality of evidence available currently, how they may be upgraded or downgraded and to decipher the positives and negatives of the common GBI scoring system, to conclude upon the final level of evidence. Future directions for developing a systematic and universal guideline to assess QoL outcomes among cochlear implantees, can be inferred from such a critical appraisal.

Keywords: Cochlear implant; Technology; Quality of life; Hearing; Auditory performance

Introduction

Cochlear implants (CI) have been established as a successful time-tested technology for restoration of hearing in persons with bilateral severe to profound hearing loss. Early intervention with cochlear implantation in pre-lingually deafened children, makes a remarkable improvement in their Quality of life (QoL), by bringing them out of the gloomy world of silence, onto the vibrant world of sound. Using implant aided hearing and with auditory-verbal training, these children develop speech and language over time, to communicate optimally and integrate into the society as normal individuals [1]. In post-lingual adults, who are un-aidable with conventional hearing aids, CI provides complete hearing restoration and hence gives them back the QoL that they experienced earlier in life [2].

Significant quality of evidence is available through quantitative data from various studies, to show that CI improves communication by restoring auditory perception and enhancing the speech quality, as measured by standardized scales like Category of auditory performance, Speech intelligibility rating, Recognition of BKB/CUNY/CNC sentences, Hearing in noise, Open set & Abstract speech understanding etc [1,3-5]. The overall impact of improvement in these measures after implantation, reflects upon better QoL. Hence, QoL measures in CI users, need to encompass all the above parameters, in order to provide reliable and valid quality of evidence.

Quality of Life Measures in Cochlear Implantees

It is believed that CI improves QoL with regards to improvement in the physical, social and mental well-being and it is of interest to analyze the quality of evidence available to support these facts. As per the Grading of recommendations assessment, development and evaluation (GRADE) working group definition, 'Quality of evidence' (QoE) is the extent to which one can be confident that an estimate of effect is correct [6]. In the context of this review, it means analysing the quality of evidence available in literature which shows improvement in QoL among CI users and critically appraising the measures which have been used to arrive at this conclusion.

Health related QoL has been measured in cochlear implantees, using generic & hearing loss specific standardized feedback questionnaires (subjective responses as per parent-reports for children; self-reported in adults). The most commonly used ones are the Glasgow benefit inventory (GBI), Glasgow health status inventory questionnaire (GHSI), Health utility index (HUI), Short-form health survey questionnaire (SF-36), KINDL questionnaire, Performance inventory for profound hearing loss (PIPHL) and Nijmegen cochlear implant questionnaire (NCIQ). These take into account the improvements in QoL with respect to auditory performance, speech intelligibility, language comprehension & expression, social interaction, cognitive & mental health, self-esteem and overall productivity of life. QoL can be measured in various ways for each of these parameters and an overall score is tabulated at periodic intervals of implant use. Hence, the quality of evidence requires to be individually graded for these measures and a consensus needs to be derived upon the overall grading. The grade of evidence is likely to be low, since the data is obtained from observational studies.

Factors which may bias the QoL measure are variables like the aetiology & duration of deafness, pre-implant amplification status, age at implantation, duration of implant use, primary communication mode, intellect, higher mental functions, associated disabilities, self-motivation, parental and social support. All these plausible confounders need to be considered while assessing the outcomes. There is no reliable or accurate pre-surgical predictor for post-surgical performance with

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CI, which can guide clinicians to predict the eventual outcomes. Outcomes for pre-lingual children versus post-lingual adults are very different and the results within these groups are quite variable. Hence, using a single standard generic questionnaire for QoL assessment in both these groups is not justifiable.

Orabi et al. studied elderly patients with presbycusis, implanted at their institution of practice [2]. They reported highly significant improvements based on self-reported measures of social, psychological and emotional aspects of quality of life. Their cohort showed no significant differences between their anticipated and actually realized functional outcomes. But, this is not always the case when it comes to QoL assessment in pre-lingually deafened children and among delayed implanted users [7,8].

An interesting paper by Warner-Czyz et al. explored the subjectivity of the feedback given by parents of CI children versus the feedback given by older CI users themselves [9]. It is inferred that while children focus on performance outcomes and physical well-being when they rate QoL, their parents reflect on their psycho-social outcomes along with their performance results. The paper concludes that there remains a need for using more than one QoL measure and multiple inputs are required to comprehensively scale all domains of CI users.

The more recent publication on QoL in CI from the same group has thrown more light upon the fact that CI has positive influence on communication, well-being and self-reliance, but these measures may still fail to correlate with the variables of age at implantation, duration of implant use, intellect and presence of co-existing disabilities. These can specifically impact the subscales of QoL measures and the overall results may be skewed due to them [10].

The very fact that numerous QoL questionnaires exist, proves that there is no single universal tool which can provide the best quality of evidence. The questionnaires are chosen in keeping with the implant specifications, based on the age and hearing-specific requirements of the individual and also as per the preference of the implant centres across the world. There is no literature available directly comparing these questionnaires with regards to their validity and reliability. Hence, a judgement needs to be made on the validity of results of individual studies and an overall strength of recommendation needs to be formulated. This review investigates the quality of evidence provided in literature in support of the Glasgow benefit inventory (GBI)-the most popular generic QoL measure available for CI users across the world [11].

Critical Appraisal of the GBI Questionnaire

GBI is a measure of patient benefit, developed especially for otorhinolaryngological interventions. It is patient-oriented and provides a common metric to compare benefit across different ENT surgeries. By providing a patient-oriented common metric, it assists in audit, research and health policy planning. It was initially designed by Robinson et al. and it was modified & adapted to assess health related quality of life outcomes in cochlear implantees by Hawthorne and Hogan [3,11]. It has 18 direct questions (with 3 sub-scales) related to the change in health and communication status due to intervention with CI. The issues addressed are related to personal satisfaction, general health status, medical issues related to implant, optimism, family support, social interaction, self-esteem, independence and job performance. The response to each question is marked on a five-point Likert scale (full failure, partial failure, no change, partial success and great success) [11]. These are then averaged to give a mean score ranging between

-100 to +100. Negative scores represent worst outcome, zero means no change and positive scores indicate benefit with CI. The net score is thus presented to the clinician, as a performance outcome with CI.

The positives of GBI

It addresses both the self-care and social life of the individual. Leading questions like willingness to undergo the procedure again & recommending CI to others, clearly document the great success which the patient has experienced. Presence of the 'no change' parameter is also a valid reflector of patient's outcomes, which signals caution to the clinician, who needs to trouble-shoot and re-program the implant to best suit the patient's needs. A negative score on GBI signifies a poor outcome, which can indicate a non-user or a device failure which needs to be addressed at the earliest.

The negatives of GBI

It does not reflect on the influence of CI on other senses like vision, balance, ambulation, dexterity, emotion, cognition & pain threshold, all of which can impact QoL. GBI does not cater to the complex needs which children with syndromic associations and multiple handicaps would require. Hence, it may not project the actual QoL experienced by this special group. In general outcomes are poor in them and GBI is unable to identify the reasons behind it.

Quality of Evidences from GBI Questionnaire

Since the GBI is scaled on an axis of -100 to +100, the maximum benefit achieved with CI, is well reflected by scores of +50 and above, while moderate benefits range between +10 to +50. The limitation of GBI is the fallacious representation of 'benefit' obtained from CI for those individuals who score <10. Even though this score indicates some positive benefit, the intervention may not be of any clinical use to them. Likewise a negative score represents that QoL has in fact deteriorated with CI, which is unlikely.

In reality, even though comparable cochlear implantees are selected by strict guidelines to receive the same type of implant and undergo same training protocols, their outcomes show wide variability over time. This inter-personal and time-bound variation results in a wide range of QoL scores, which when statistically analysed may increase the standard deviations and standard error of means, leading to reduced validity and reliability. This has been elucidated in a recent publication by Sanchez-cauadrado et al., who observed a wide range of standard deviations as below [12]. In their study, the mean total score (mean \pm standard deviation) of the GBI was 35.1 ± 23.6 , and its sub-sets showed 47.6 ± 28.9 for General Health, 17.9 ± 33.2 for Social Benefit and 11.7 ± 27.9 for Physical Health. The reliability was above 0.70 in all test domains, which does support the fact that GBI is a valuable tool for measuring QoL in CI.

The major drawback for GBI measures in CI is the smaller samples available in literature, which reduces the strength of the evidence. The quality of evidence available for pre-lingually deafened children using CI (especially those who receive bilateral implants), is better than for adult users. The strength of evidence for kids is due to the availability of larger age-matched data samples, quantifying improvement in QoL, sequentially recorded with intensive auditory-verbal therapy. On the contrary, GBI measures in adult CI users with prolonged periods of hearing loss have been variable. The data available is sparse & inconsistent for this special group, to confirm reliable improvement in their QoL.

Upgrading Quality of Evidence in GBI Questionnaire

Incorporating qualitative data using patient's personal inputs rather than asking them to score only on the Likert's quantitative scale, improving directness with custom-made open-ended questions for children/adult users, creating age-dependant gradients for observations and expanding the range of questions to include psycho-social impacts of CI will upgrade the quality of evidence. Unfortunately, a randomized control trial which can provide high grade of evidence is not possible for assessing QoL in CI users, but consistency across two or more observational studies with increased samples, should upgrade quality of evidence.

Downgrading Quality of Evidence in GBI Questionnaire

Quality of evidence may get downgraded by including improper or small study samples (not age matched/lingual status matched), lack of clarity in questions addressing specific concerns of the individual, probability of reporting bias with subjective responses being influenced by carers/parents and if there is poor validity and test-retest reliability, due to inconsistent responses recorded over time.

Conclusion

Cochlear implants have a positive influence not only on the health related QoL, but also on the psycho-social domain of the individual, which improves over time of implant use. Numerous QoL questionnaires have been developed over the years providing a variety of results. In general, literature states that CI improves QoL, but there is no categorical paper comparing the various methods to arrive at a consensus of opinion. Since the grade of evidence available is low, it is vital to compare the various QoL measures available, in order to identify the most reliable & valid method which can be recommended for clinical practice in the future.

Recommendations

Generic & disease specific QoL measures used in CI users have focused on health related improvements, but there remains the need for a holistic tool, which can candidly capture the way CI influences every aspect of life. Focusing on issues specific to CI like self-reliance, social relations, education, effects of implantation and social acceptance in society, may provide a more accurate and relative view of functional status of CI users.

Future direction will be to develop such a comprehensive QoL questionnaire, custom-made with specific open-ended questions individually addressing the salient concerns for the different groups of

CI users-1) pre/peri-lingual deafened children, 2) pre-lingual deafened syndromic children with multiple handicaps, mental disabilities or complex needs, 3) early deafened delayed implanted adults using lip reading/sign language skills and 4) post-lingual adults with short period of deafness. Such questionnaires will cater to the individual needs for optimizing rehabilitation strategies and will enhance the validity & reliability of QoL measures for CI users. In summary, further research in this realm is very likely to have an important impact on the quality of evidence and thereby influence a change in practice in the future.

Conflict of interest

Nil.

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