



Cochlear Implants International

An Interdisciplinary Journal

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/ycii20>

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To cite this article: Anuradha R. Bantwal, Rashmi Deshpande, Rewa Indurkar, Salaj Bhatnagar, Meenakshi Wadhera, Aditya Sridhara, Neera Lalwani, Asha Agarwal, Ramesh K. Oza, Neevita Narayan, P. Sasidharan, B. Mallikarjun, Chandan Saha, Priya Bhale, Shweta Deshpande & Kalyani Mandke (2021): A study of self-perception and communication success as perceived by adolescents with cochlear implants and their significant others, Cochlear Implants International, DOI: [10.1080/14670100.2021.1875577](https://doi.org/10.1080/14670100.2021.1875577)

To link to this article: <https://doi.org/10.1080/14670100.2021.1875577>



Published online: 26 Feb 2021.



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A study of self-perception and communication success as perceived by adolescents with cochlear implants and their significant others

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Objectives: The objectives of this prospective, cross-sectional study were to compare self-perception and communication-success ratings of adolescents with cochlear implant (AWCI) and their caregivers (C-AWCI) and to explore associations with age at CI, implant age, and chronological age.

Method: Fourteen CI centers across India participated. The Think About it Quiz (TAIQ), Self Assessment of Communication-Adolescent (SAC-A), and Significant Other Assessment of Communication-Adolescent (SOAC-A) were translated into five languages. Data were collected from 173 AWCI aged 10;0–19;6 years and an associated caregiver for each participant.

Results: On the TAIQ, self-ratings by AWCI were significantly lower than the ratings by C-AWCI. Peer acceptance correlated with athletic competence for both groups. For the SAC-A versus SOAC-A, there was no significant difference between AWCI and C-AWCI ratings. Except for a negative correlation between peer-acceptance and chronological age for caregiver ratings, no other associations were found between any other ratings and age at CI, implant age, and chronological age.

Conclusions: Caregiver judgments of their adolescents with CI were not in equal agreement with self-ratings by the adolescents across various aspects of performance. Caregivers appeared to underestimate the self-perception issues faced by adolescents with CI but had excellent agreement with their adolescents' self-rating of communication success. The inclusion of activities to improve children's participation in sports could possibly improve peer acceptance.

Keywords: Implant age, Think About it Quiz, Self Assessment of Communication-Adolescent, Significant Other Assessment of Communication-Adolescent, Adolescent with cochlear implant, Caregivers of adolescents with cochlear implant

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Introduction

Cochlear implant (CI) is an accepted method of intervention for children with a severe to profound hearing loss. Studies have documented that CI followed by suitable habilitation leads to significant gains and achievements in several domains including auditory speech perception, speech and language development, social development, and education (e.g. Beadle *et al.*, 2005; Niparko *et al.*, 2010; World-Health-Organization, n.d.-a). However, it is known that the outcomes from CI are variable across children and depend on a range of child- and environment-related factors (e.g. Boons *et al.*, 2012; Geers *et al.*, 2009; Lund, 2016).

In addition to speech-language outcomes and speech perception, researchers have increasingly been investigating other performance-indicators such as overall quality of life (QoL), peer-relationships, well-being, self-identity, and self-perception. Several studies have addressed these aspects (e.g. Kumar *et al.*, 2015; Loy *et al.*, 2010). Many of the QoL studies reflect caregiver perspectives while comparatively few such as Loy *et al.* (2010) and Marschark *et al.* (2012) have documented children's self-perception.

Currently a significant number of pediatric CI recipients in India have used their devices for several years and are now adolescents or adults. Adolescence is a challenging period for all including typically hearing and developing individuals. According to Gutsgesell and Payne, 'Although some recent data show that 75% of adolescents and their families have a transitional experience that is trouble-free, many have described this period as one of "storm and stress"' (Gutsgesell and Payne, 2004, p. 79). Developmental changes in the adolescent years may 'elevate the risk for physical isolation, and increase the chances that these experiences will be perceived as social isolation and interpreted as loneliness' (Laursen and Hartl, 2013, p. 1261). Robins *et al.* (2002) studied self-esteem over the lifespan and reported that, in adolescence, there was a drop in scores compared to childhood and adulthood.

The issues related to adolescence may be heightened in individuals with hearing loss due to various factors (Brice and Strauss, 2016). Punch and Hyde (2011b) interviewed parents of children and adolescents with CI. They found that, although CI resulted in significant gains in language, communication and speech, there were persistent concerns surrounding social situations, friendship patterns, and common adolescent issues. Punch and Hyde surveyed the responses of 247 parents of children who received CI under the age of 18 years; also 151 teachers who had worked with children with CI. Further, they collected inter-

view data from 11 CI users aged 10–17 years. They reported their findings through two publications (Punch and Hyde, 2011a, 2011b). Parents had significant concerns about their children's social skills and social participation as it affected peer acceptance and inclusion. Teacher ratings indicated lower performance compared to parent ratings. According to teachers one-third of the children did not easily make friends with hearing children, had social skills that were not age appropriate, and 10% were not accepted by hearing peers. The authors suggested that the success of children with CI in 1:1 communication appeared to mask their difficulties in group situations when they were rated by their parents. In other words, parents might base their opinions on their own interactions with the child within the family which are less complex compared to the group situations that children face in school.

The studies mentioned above collectively highlight the importance of more research in the area of long-term outcomes of CI. Self-report questionnaires are important to collect these types of data.

Objectives

Based on a review of the literature, few studies compare self-reported and caregiver-reported ratings in adolescents with CI. The present study included adolescents who were experienced CI users as the target group, for two reasons: (1) it is an age-group from whom in-depth self-report was feasible and (2) as revealed by the review of literature, adolescence is a sort of 'high-risk' but crucial age in which the individual needs to acquire several readiness skills for adulthood. The specific objectives of the study were: (1) to understand how adolescents with cochlear implant (AWCI) rate themselves on questionnaires related to self-perception and communication-success; (2) to compare the self-report of AWCI with that of their caregivers (C-AWCI) on the same questionnaires; and (3) to explore association of these ratings with age at CI, implant age, and chronological age.

Methods

This was a prospective, cross-sectional study seeking to investigate self-perception and communication-success of AWCI, as evaluated by the recipients themselves and by their significant others. According to the definition given by the World Health Organization (n.d.-a), individuals between 10 and 19 years of age were considered as 'adolescents' for the purposes of the present study.

This study was multi-centric. Fourteen CI centers from seven States across India signed a

Memorandum of Understanding (MoU) to participate in the study. The distribution of centers across States was as follows: Maharashtra (5), West Bengal (1), Gujarat (1), Karnataka (1), Delhi (3), Madhya Pradesh (2), and Kerala (1). Ethics clearance was sought from and given by an independent institutional ethics committee.

Participants

Participants included AWCI, ages 10;0 to 19;11 years as well as an associated caregiver (C-AWCI) for each participant. The AWCI had prelingual hearing loss with a minimum of 5 years CI use. C-AWCI was defined as a significant other who had been most involved in the intervention of the AWCI.

The AWCI group included those with unilateral CI not using amplification in the contralateral ear, those with bilateral CI, and also bimodal users (CI in one ear and hearing aid in the other ear). Individuals with less than 5 years of experience with CI, those with any cognitive-related or additional diagnoses, and those with post-lingual hearing loss were excluded from the study.

Materials and tools

A data capture form was created to obtain the following information about each participant: relevant demographic data; details pertaining to the CI device and surgery; and 25 questions/ statements seeking details of the recipients' device usage profile, communication profile, and educational history. Consent and assent forms for participation were made as per WHO guidelines (World-Health-Organization n.d.-b). Three questionnaires were selected for use in this study with due permission from their authors: the Think About it Quiz (TAIQ) (Anderson, 2013), the Self Assessment of Communication-Adolescent (SAC-A) (Elkayam and English, 2011a) and the Significant Other Assessment of Communication-Adolescent (SOAC-A) (Elkayam and English, 2011b).

Think About it Quiz (Anderson, 2013)

This questionnaire seeks the participant's self-rating in five major domains, namely, athletic competence, conduct/morality, peer acceptance, physical appearance, and scholastic competence with six affirmative statements per category. The responses are on a 5-point Likert scale where the participant is expected to tick the choice that best describes their opinion on the statement (strongly disagree/disagree/neither agree nor disagree/agree/strongly agree). The following rating is used for scoring: 1 = Strongly disagree; 2 = Disagree; 3 = Neither agree nor disagree; 4 = Agree; 5 = Strongly agree. Based on the above system the score for a participant can range from a minimum of 5 to a maximum of 30 per domain.

Anderson (2013) suggested that a score of 17 or less on any domain indicated a negative self-concept.

For the present study data were collected on the TAIQ for all AWCI. Additionally, as suggested by Dr. Karen Anderson (2016 personal communication), the questionnaire was also separately answered by each caregiver with reference to their child. This enabled paired comparisons between the scores given by the AWCI and their caregivers.

Self Assessment of Communication-Adolescent (Elkayam and English, 2011a) and Significant Other Assessment of Communication-Adolescent (Elkayam and English, 2011b)

These questionnaires both have the same points addressing success in communication. The former elicits the individual's self-perception and the latter elicits a significant other's perception about the same points. When both are administered, they yield a paired comparison of scores between the responses of the individual with hearing loss and their significant other. The sub-areas under which the statements are placed are: hearing and understanding at different times; feelings about communication; and communication success with other people. The questionnaires as explained by the authors (Elkayam and English, 2011a, 2011b) help in gaining information to assist professionals in managing communication issues faced by adolescents with hearing loss.

Both questionnaires have the same 12 questions. In the SAC-A, the questions elicit the individual's opinion about themselves (e.g. Is it hard for you to understand when talking with only one other person?) while in the SOAC-A the questions elicit the opinion of the significant other (e.g. Is it hard for your friend to understand when talking with only one other person?). In the present study, the 'significant other' questionnaire was filled by a caregiver and not a hearing peer as in the original by Elkayam and English.

The responses are on a 5-point Likert scale where the participant is expected tick the choice that best describes their opinion on the statement (almost never/occasionally/about half the time/frequently/almost always). The following rating is used for scoring: 1 = almost never; 2 = occasionally; 3 = about half the time; 4 = frequently; 5 = almost always. The higher the score, greater would be the difficulties faced in daily communication.

Translation of tools

The English versions of the data capture form, consent/assent forms and questionnaires (TAIQ, SAC-A and SOAC-A) were all translated into four languages namely Marathi, Hindi, Kannada, and Gujarati by professional translators. Reverse

translation was done by a separate set of native adult speakers to evaluate the accuracy of translation. To ensure that the language was understandable to children with CI, three participants from each language background were administered the questionnaire. The questionnaires were administered through face-to-face interview, emailed forms, and through filling out a print version depending on the individual participant's convenience.

Results

A total of 173 caregiver-adolescent dyads from 14 CI centers across India participated in this study. Out of 173 AWCI participants, 95 were male and 78 were female. The AWCI ranged in age from 10 to 19.60 years ($Mean = 13.88$; $SD = 2.55$; $Md = 13.26$). Age at CI ranged from 1.25 to 12.93 years ($Mean = 4.70$; $SD = 2.79$; $Md = 3.94$), and implant age (i.e. number of years elapsed since CI) ranged from 5 to 16.2 years ($Mean = 9.20$; $SD = 2.59$; $Md = 8.75$).

Think About it Quiz (Anderson, 2013)

The output of the TAIQ was analyzed for the following in each of the 5 sub-areas of the questionnaire: (1) to explore differences between the responses of AWCI and their caregivers (C-AWCI); (2) to analyze correlations between scores in different sub-areas with age at CI, implant age, and chronological age; and (3) to analyze correlations between scores in different sub-areas for each group i.e. AWCI and C-AWCI.

Studying gender differences was not a specific objective of this study. Hence care was taken to include sufficient participants of both genders. As the TAIQ was related to self-perception which could be sensitive to gender effects, a preliminary analysis for gender differences was conducted to ensure that data from males and females could be combined. The analysis indicated no significant difference in scores between genders for any domain except scholastic competence for AWCI and conduct/morality

when rated by the C-AWCI. As there was no trend for gender difference across different domains of the TAIQ, and the means, medians, and ranges were very similar, the data from males and females were combined for all further analysis. The descriptive statistics for the scores of both groups (AWCI and C-AWCI) are given in Table 1.

Differences between the responses of AWCI and the C-AWCI on the TAIQ

The descriptive statistics indicated that for all 5 sub-areas the ratings given by the caregivers were higher than those given by the AWCI themselves. Figures 1A and B to 5A and B illustrate the difference graphically through histograms. For each figure compare 'a' versus 'b'. The histograms represent the number of participants who gave each rating. For all five sub-areas, comparison of the histograms of the AWCI versus C-AWCI shows that the ratings by caregivers were clustered towards the right (higher scores).

The AWCI rated themselves much lower on all domains compared to the ratings that their caregivers gave them. Anderson (2016 personal communication) suggested that a score of 17 or less on any domain of the TAIQ was cause for concern. For athletic competence, 107 of 173 AWCI rated themselves ≤ 17 while only 7 caregivers gave ratings in this range. For conduct/morality 80 AWCI rated themselves ≤ 17 as against just 1 caregiver. For peer-acceptance, these numbers were 89 for AWCI and 4 for the C-AWCI. In the domain of physical appearance, 71 AWCI gave themselves ratings of 17 or less while only one caregiver gave a rating in this range. Finally for scholastic competence, the numbers were 81 for AWCI versus 5 for C-AWCI. These numbers and the graphical information provided by the histograms display the significant difference in the pattern of responses of the AWCI versus their caregivers.

The ratings given by the AWCI and C-AWCI were treated as paired data and analyzed using the

Table 1 Descriptive statistics of the TAIQ for AWCI and C-AWCI

		Athletic Competence			Conduct /Morality			Peer Acceptance			Physical Appearance			Scholastic Competence		
		M	F	C	M	F	C	M	F	C	M	F	C	M	F	C
AWCI	N	95	78	173	95	78	173	95	78	173	95	78	173	95	78	173
	Mean	16.89	16.33	16.64	17.55	17.46	17.51	17.01	16.79	16.91	17.73	17.41	17.58	16.79	17.47	17.10
	SD	2.10	2.38	2.24	1.81	1.70	1.75	2.23	2.35	2.28	2.16	2.50	2.32	2.30	2.11	2.24
	Median	17.00	17.00	17.00	18.00	18.00	18.00	17.00	18.00	17.00	18.00	18.00	18.00	17.00	18.00	18.00
	Min	11.00	10.00	10.00	13.00	12.00	12.00	10.00	10.00	10.00	12.00	6.00	6.00	8.00	10.00	8.00
C-AWCI	N	95	78	173	95	78	173	95	78	173	95	78	173	95	78	173
	Mean	21.07	20.74	20.92	22.29	22.92	22.58	21.56	21.18	21.39	23.56	23.83	23.68	21.76	22.18	21.95
	SD	2.27	2.59	2.41	2.53	2.58	2.56	2.30	2.22	2.26	3.18	3.09	3.13	2.37	2.71	2.52
	Median	21.00	21.00	21.00	22.00	23.00	22.00	22.00	21.00	21.00	23.00	24.00	24.00	22.00	22.00	22.00
	Min	17.00	14.00	14.00	18.00	17.00	17.00	17.00	15.00	15.00	18.00	16.00	16.00	17.00	17.00	17.00
Max	30.00	29.00	30.00	30.00	30.00	30.00	27.00	29.00	29.00	30.00	30.00	30.00	30.00	30.00	30.00	

Note: M: Male; F: Female; C: Combined for male and female.

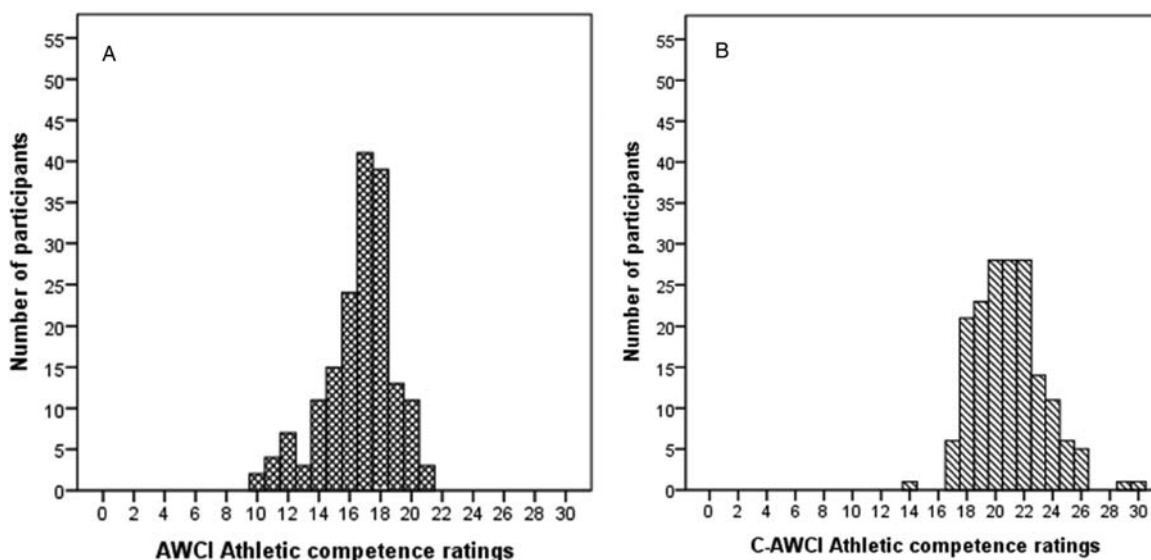


Figure 1 Histograms of athletic competence ratings by AWCI (A) and their caregivers (B).

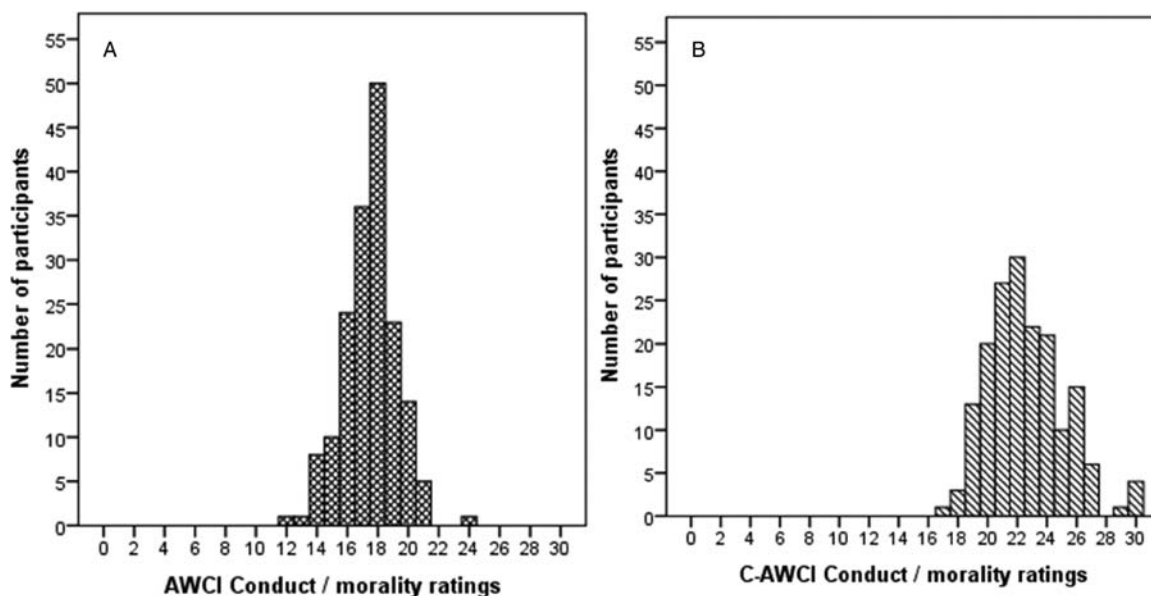


Figure 2 Histograms of conduct/morality ratings by AWCI (A) and their caregivers (B).

Wilcoxon signed ranks test. For all five sub-areas of the TAIQ, there was a statistically significant difference in the ratings by the AWCI versus their caregivers: athletic competence [$Z = -11.16, P = 0.000, r = -0.60$]; conduct/morality [$Z = -11.27, P = 0.000, r = -0.61$]; peer-acceptance [$Z = -11.23, P = 0.000, r = -0.60$]; physical appearance [$Z = -11.08, p = 0.000, r = -0.59$] and scholastic competence [$Z = -11.22, P = 0.000, r = -0.60$]. For all the differences, effect sizes were large ($r \geq 0.5$) according to Cohen (1992 cited in Field, 2009, p. 57).

Correlational analysis was also done for these comparisons to check whether lower ratings by AWCI were associated with lower ratings by C-AWCI. This was done because correlation may be present even if there is a large difference in the paired comparison. The analysis indicated significant positive correlations

between the ratings by AWCI and C-AWCI for all sub-areas of the TAIQ except physical appearance. The values of the significant correlations were as follows: athletic competence ($r_s = 0.341, P = 0.000$); conduct/morality ($r_s = 0.184, P = 0.015$); peer-acceptance ($r_s = 0.242, P = 0.001$); and scholastic competence ($r_s = 0.318, P = 0.000$).

Correlations between scores in different sub-areas of the TAIQ with age at CI, implant age and chronological age

Overall, there was no significant correlation between the ratings by AWCI on any of the sub-areas of the TAIQ, with age at CI, implant age, or chronological age. For C-AWCI, there was similarly no correlation on any area of the TAIQ with age at CI or implant age. Chronological age showed significant negative

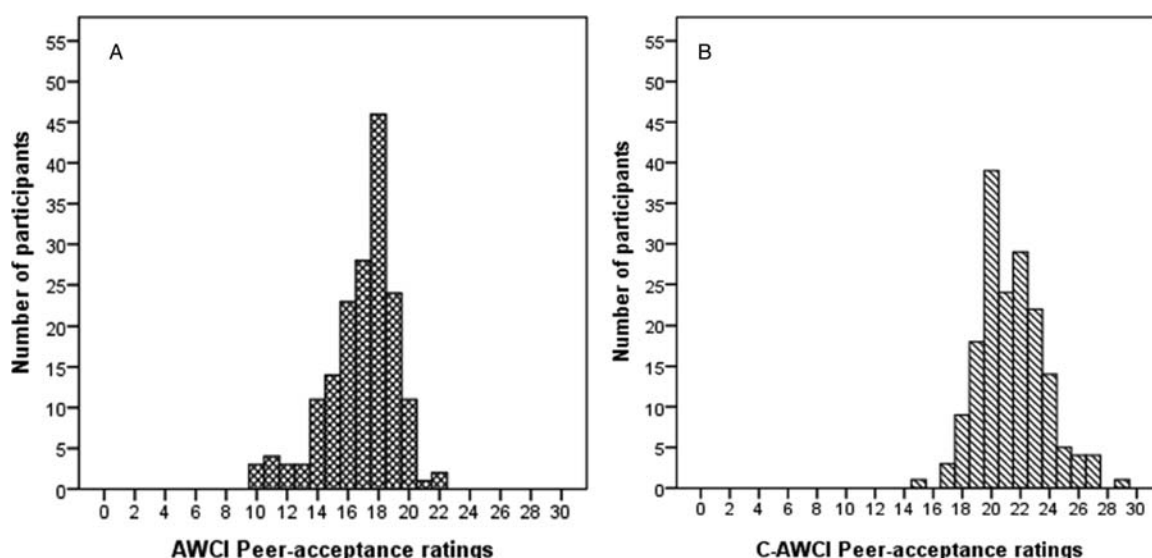


Figure 3 Histograms of peer-acceptance ratings by AWCI (A) and their caregivers (B).

correlation only with peer-acceptance ($r_s = -0.21$, $P = 0.01$) for Bonferroni corrected $\alpha = 0.01$.

Correlations between scores in different sub-areas of the Think About it Quiz for AWCI; and C-AWCI

Spearman’s correlation coefficient (rho) was determined between different sub-areas for the AWCI as well as the C-AWCI (refer to Table 2). The implication of the results is elaborated in the discussion.

Self Assessment of Communication-Adolescent (SAC-A) and Significant Other Assessment of Communication-Adolescent (SOAC-A)

In this study, we treated the total scores for each sub-area of the SAC-A and SOAC-A, as paired data. Only the first five of six questions from the first sub-area were used for analysis although data were collected

for all six. The sixth question was not included in the total score for the section. The question, ‘Do you hear better when using your hearing aids or cochlear implants?’ would result in a score in a direction opposite to the other five (1 = almost never and 5 = almost always). For the first five questions a score of ‘1’ meant best performance whereas it would mean the opposite for the sixth question.

Hence for the first sub-area, i.e. ‘hearing and understanding’, the score in our study could range from 5 to 25. For the other two sub-areas, i.e. ‘feelings about communication’, and ‘communication success with other people’ the scores could range from 3 to 15. The descriptive statistics of the scores for both groups on the three sub-areas of the questionnaire are detailed in Table 3.

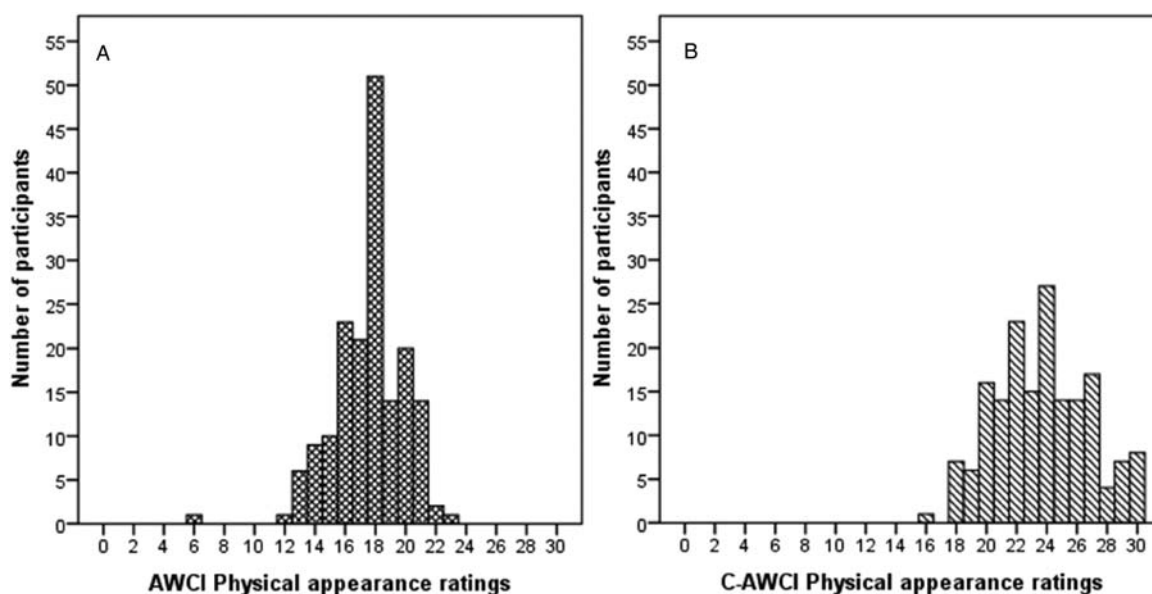


Figure 4 Histograms of physical appearance ratings by AWCI (A) and their caregivers (B).

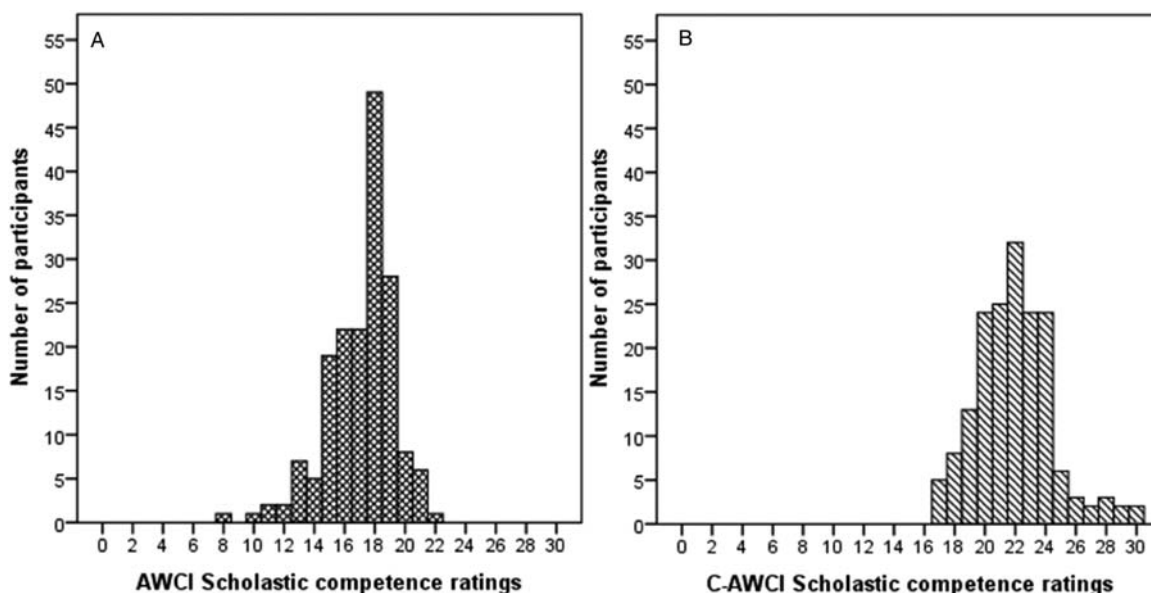


Figure 5 Histograms of scholastic competence ratings by AWCI (A) and their caregivers (B).

The values in the table suggest similarity in the ratings given by the AWCI and their caregivers. The similarity in rating patterns of the AWCI and their caregivers is also apparent from the histograms in Figs. 6A and B to 8A and B.

Before pooling data from males and females, independent samples Mann–Whitney U tests were used to analyze gender difference. For sub-area 1 (hearing and understanding) and sub-area 2 (feelings about communication), there were no significant differences for either the AWCI or their caregivers. For sub-area 3 (communication success with other people), although the gender difference was significant for the AWCI [$U = 3008.00, Z = -2.142, P = 0.032, r = -0.16$] as well as the C-AWCI [$U = 2578.50, Z = -3.462, P = 0.001, r = -0.26$], the patterns of scores were same for both groups (refer to the data in Table 3). Hence it was decided to pool

the data from both genders for comparison between SAC-A and SOAC-A.

The data were analyzed for the following in each of the 3 sub-areas: (1) to explore differences between the responses of AWCI (SAC-A) and their caregivers (SOAC-A); (2) to analyze correlations between scores in different sub-areas with age at CI, implant age and chronological age; and (3) to analyze correlations between scores in the three sub-areas for each group i.e. AWCI and C-AWCI.

Differences between the responses of AWCI (SAC-A) and their caregivers (SOAC-A)

Wilcoxon signed ranks tests were used to analyze paired differences in scoring patterns between the AWCI and their caregivers. The results indicated no significant difference in the scores (i.e. AWCI and C-AWCI) for any of the three sub-areas,

Table 2 Correlations between scores in different sub-areas of the TAIQ for AWCI; and C-AWCI

		Conduct/morality	Peer-acceptance	Physical appearance	Scholastic competence
AWCI	Athletic competence	$\rho = 0.137$	0.383*	0.113	0.232*
		Sig	0.073	0.140	0.002
	Conduct/morality	$\rho = 0.097$	0.204	0.051	0.158
		Sig	0.509	0.509	0.038
	Peer-acceptance	$\rho = 0.166$		0.166	0.312*
		Sig	0.029	0.029	0.000
C-AWCI	Physical appearance	$\rho = 0.201$			0.201
		Sig	0.008		0.008
	Athletic competence	$\rho = 0.265^*$	0.293*	0.279*	0.126
		Sig	0.000	0.000	0.099
	Conduct/morality	$\rho = 0.317^*$	0.317*	0.337*	0.138
		Sig	0.000	0.000	0.070
	Peer-acceptance	$\rho = 0.16$		0.16	0.059
		Sig	0.035	0.035	0.438
	Physical appearance	$\rho = 0.327^*$			0.327*
		Sig	0.000		0.000

Note: Significance was tested at a Bonferroni corrected $\alpha = 0.005$, Correlations in bold with '*' indicate significant values.

Table 3 Descriptive statistics for SAC-A (AWCI) and SOAC-A (C-AWCI)

		Sub-area 1			Sub-area 2			Sub-area 3		
		M	F	C	M	F	C	M	F	C
SAC-A (AWCI)	N	95	78	173	95	78	173	95	78	173
	Mean	11.90	12.62	12.76	6.96	6.95	6.95	7.22	6.35	6.83
	SD	4.79	4.34	4.58	2.81	2.86	2.83	2.94	2.92	2.95
	Median	12.00	12.00	12.00	6.00	6.00	6.00	7.00	6.00	6.00
	Min	6.00	5.00	5.00	3.00	3.00	3.00	3.00	3.00	3.00
	Max	25.00	23.00	25.00	15.00	15.00	15.00	14.00	14.00	14.00
SOAC-A (C-AWCI)	N	95	78	173	95	78	173	95	78	173
	Mean	13.20	12.83	13.03	7.18	6.91	7.06	7.16	5.92	6.60
	SD	4.60	4.18	4.41	2.60	2.84	2.71	2.57	2.59	2.65
	Median	12.00	12.00	12.00	7.00	6.00	7.00	7.00	7.00	6.00
	Min	5.00	5.00	5.00	3.00	3.00	3.00	3.00	3.00	3.00
	Max	24.00	23.00	24.00	15.00	15.00	15.00	14.00	14.00	14.00

Note: M: Male; F: Female; C: Combined for male and female; Sub-area 1 = Hearing and understanding; Sub-area 2 = Feelings about communication; Sub-area 3 = Communication success with other people.

namely hearing and understanding at different times ($Z = -1.535$, $P = 0.125$); feelings about communication ($Z = -0.5140$, $P = 0.607$); and communication success with other people ($Z = -1.329$, $P = 0.184$). Correlation analysis using Spearman’s rho indicated significant positive correlation between the scores of AWCI and C-AWCI in all three sub-areas namely hearing and understanding at different times ($r_s = 0.679$, $P = 0.000$); feelings about communication ($r_s = 0.543$, $P = 0.000$); and communication success with other people ($r_s = 0.409$, $P = 0.000$).

Correlations between scores in different sub-areas of the SAC-A and SOAC-A with age at CI, implant age and chronological age

Age at CI, implant age and chronological age did not correlate significantly with the scores on any of the three sub-areas for a Bonferroni corrected $\alpha = 0.016$.

Correlations between scores in different sub-areas of the SAC-A and the SOAC-A

All correlations between sub-areas were significant and positive (at corrected $\alpha = 0.016$) for both SAC-A as well as SOAC-A. The correlation values were as follows for SAC-A: sub-area 1 with 2 ($r_s = 0.579$, $P = 0.000$); sub-area 1 with 3 ($r_s = 0.491$, $P = 0.000$) and sub-area 2 with 3 ($r_s = 0.535$, $P = 0.000$). For the SOAC-A, the values were: sub-area 1 with 2 ($r_s = 0.647$, $P = 0.000$); sub-area 1 with 3 ($r_s = 0.582$, $P = 0.000$) and sub-area 2 with 3 ($r_s = 0.596$, $P = 0.000$).

Discussion

For all sub-areas of the TAIQ, the ratings given by caregivers were significantly higher than self-ratings by the AWCI (refer to the descriptive statistics in Table 1 and the histograms in Figs. 1–5). Significant positive correlations between scores of AWCI and C-AWCI for all areas of the TAIQ except physical

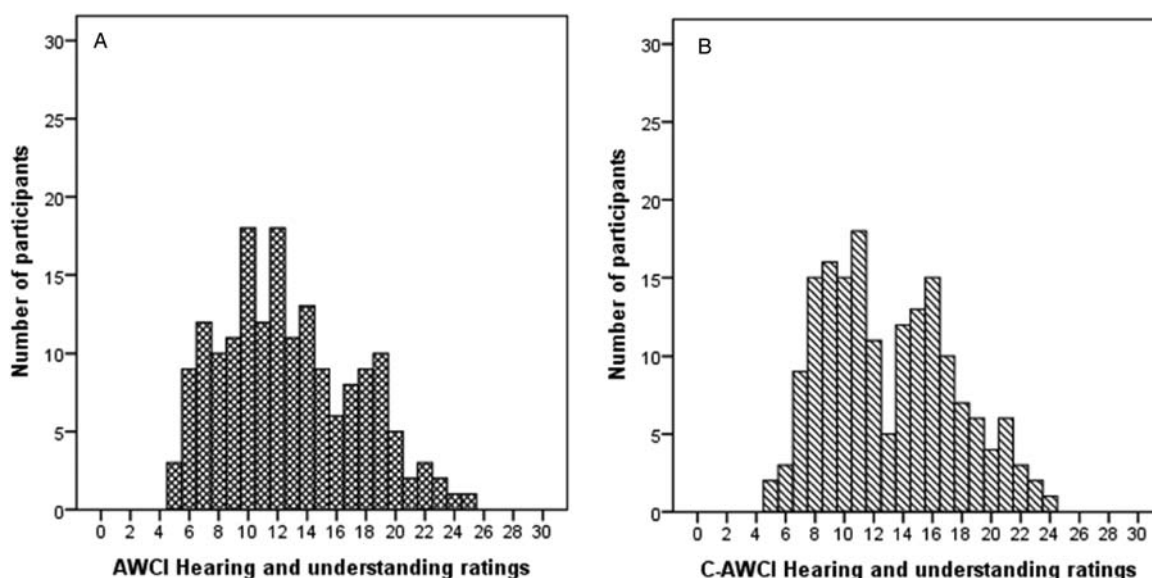


Figure 6 Histograms of ‘hearing and understanding’ by AWCI (A) and their caregivers (B).

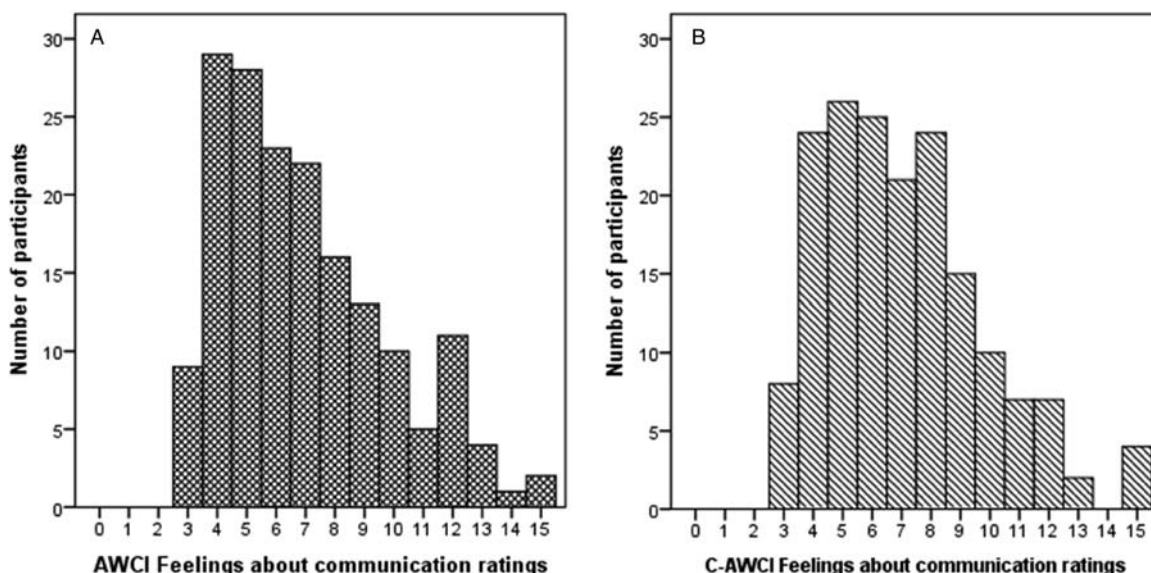


Figure 7 Histograms of ‘feelings about communication’ by AWCI (A) and their caregivers (B).

appearance imply that although the ratings of the two groups differed, higher ratings by AWCI on any aspect were associated with higher ratings by the C-AWCI. Thus, caregivers in general did know the strengths and weaknesses of their adolescents, although they might score their performance more generously.

A study by Razafimahefa-Raoelina *et al.* (2016) reported that at 3 years post CI, children with CI had a quality of life close to that of their hearing peers. They used the Kidscreen 27 questionnaire for their study. Although we used a different questionnaire for the present study, it did explore common areas of physical and psychological well-being and also peer relationships. Razafimahefa-Raoelina *et al.* reported contrary to the present study, that parents underestimated their children’s QoL.

There was no pattern of correlation between AWCI ratings on the TAIQ and age at CI, implant age, or chronological age. For C-AWCI, only the correlation between chronological age and peer acceptance was significant and negative. This indicated that as per caregiver perception, higher chronological age was associated with lower peer acceptance i.e. older adolescents faced greater issues with acceptance. It is not clear how much importance should be given to this isolated findings when no such trend was visible for AWCI ratings or even the C-AWCI ratings when correlated with age at CI and implant age. Overall, the lack of correlation between age at CI and performance on the TAIQ was surprising given that the advantages of early CI are very well documented in the literature. The proposed reasons for the present study not showing that relation are as follows: the

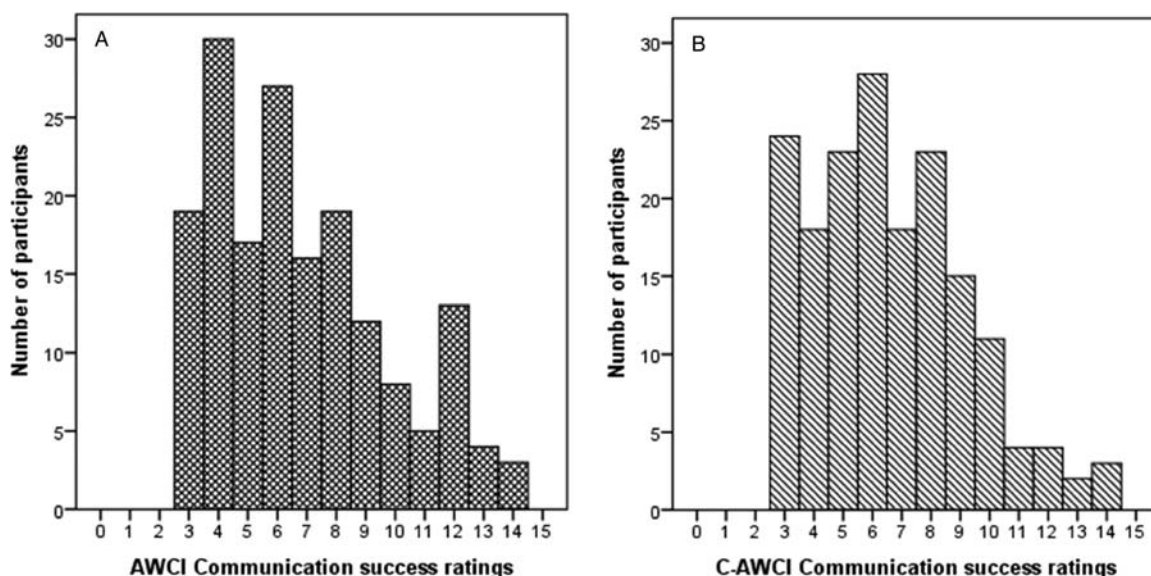


Figure 8 Histograms of ‘communication success’ by AWCI (A) and their caregivers (B).

TAIQ may not be the most sensitive or appropriate tool for demonstrating the advantages of earlier CI as it contains skills whose development is not exclusively dependent on hearing and language levels. Further, our study did not control the number of adolescents receiving CI at different ages. All adolescents with prelingual (congenital, acquired, or progressive) hearing loss were included provided they had used the CI for 5 years or more.

For the AWCI, peer acceptance was associated with higher ratings on athletic and scholastic competence. Caregiver ratings also reflected the same trend for athletic but not scholastic competence. Further, the C-AWCI ratings indicated that adolescents with higher ratings on conduct/morality had better peer acceptance. It was heartening to note that neither AWCI nor C-AWCI scores reflected association between peer acceptance and physical appearance. Our study did not include data of language performance which could be an underlying factor affecting performance in any or all the sub-areas that are included in the TAIQ.

Bat-Chava and Deignan (2001) reported that oral communication ability had significant association with peer relationships. Further, the authors mentioned that parents had concerns about loss of MAP due to static interference from play equipment, and injury during sports. In our study, caregivers rated their children significantly higher on athletic competence than what the adolescents rated themselves. Perhaps, the AWCI could compare themselves better with peers on this dimension whereas caregivers might have been just 'happy and satisfied' with whatever their child could do and were more focused on the satisfaction from post CI hearing, speech, language and communication benefits. It is possible that caregiver apprehensions about injuries, processor damage etc could lead to them restricting their CI children's participation in non-supervised play and sports, in turn limiting their opportunities to form peer relationships.

What is worrisome in the outcome of the TAIQ is that the means and medians for ratings by the AWCI were close to 17 which was proposed as a cut-off by Anderson (2016 personal communication) for identifying children whose ratings were of concern. Sixty-two percent of AWCI had ratings ≤ 17 for athletic competence. We propose a few possible reasons for this poorer performance other than the ones listed above. Post-CI, caregivers are focused on core aspects such as therapy, schooling, remedial education, and special support for the children to cope in classrooms. Sports and play are comparatively 'lower-priority' areas. In children with poor communication, the inability to understand rule based games could impede participation and in the long term, acceptance, by hearing peers. Parents often say

that other children don't include their child because they do not understand the game or that the other children are 'too quick' in their play related discussions which the child with CI can't keep up with. CI in India has been largely self-funded or funded through charity. Government funding for CI and post-CI habilitation has become available only recently, and is mainly intended for families in the low income group. As mapping, therapy, repairs, maintenance, upgrades, out of warranty internal device failure etc also need to be budgeted for, enrolling children for sports coaching or other extracurricular activities could be a luxury for many families.

Fifty-one percent of AWCI had ratings ≤ 17 for peer acceptance. Taken together with the finding that correlation between peer acceptance and athletic competence was significant for AWCI as well as C-AWCI, it suggests that habilitation goals should specifically include improving the ability to participate in games and sports. Caregivers should also be specifically counseled about the importance of play and sports in their child's development and societal integration. Conduct/morality and scholastic competence ratings by the AWCI were marginally better with 54% and 53% respectively giving themselves ratings above 17. Physical appearance had the smallest percentage of low ratings (41% of 173).

The TAIQ ratings by caregivers portrayed a very different profile and reflected much lesser cause for concern. The means and medians for C-AWCI were well above 17 and a very small proportion of caregivers gave low ratings. Hence the agreement between C-AWCI and AWCI was low. From caregiver perspective the highest percentage ratings ≤ 17 were observed for athletic competence just as for AWCI, but for only 4% of 173 caregivers. Scholastic competence was rated ≤ 17 by approximately 3% of the C-AWCI; peer-acceptance by only about 2%; while conduct/morality and physical appearance were both rated ≤ 17 by only 0.5% of 173 AWCI.

Age at CI and implant age were not significantly correlated with performance on any of the sub-areas of the SAC-A or the SOAC-A. The reasons would be the same in general as those discussed for the TAIQ where no pattern of correlation was observed either. Also perhaps, success in a variety of communication situations may be mediated by factors other than merely auditory, speech, and language skills. Subtle individual factors such as motivation, persistence, communication attitude, self-confidence, ability to use top-down processes, visual communication, and cognitive ability would also contribute to overall communication success.

Comparison of the analyses on the TAIQ versus the SAC-A and SOAC-A indicates a difference in the

caregivers' ability to perceive issues faced by AWCI across difference areas of performance. Tangible aspects such as communication difficulties appeared to be closely observed and tracked by caregivers because perhaps these are traditionally considered to be the 'core' issues caused by hearing loss. Caregivers seemed less knowledgeable about issues faced by their children in relatively abstract aspects such as athletic competence, conduct/morality, peer acceptance, and physical appearance. Scholastic competence ratings is a sub-area where caregiver judgment should have tallied with that of the AWCI, but this was not the case. Not only were the self-perceived ratings of AWCI significantly lower than those by caregivers, the effect size was large at 0.6. This indicated that caregivers' thoughts about their children's scholastic competence were very different from those of the children themselves. Did caregivers base their higher ratings on the grades that their children received and their expectations that the adolescent was doing well enough 'all things considered', while the adolescents' were more likely to compare themselves with hearing peers and consider aspects such as daily classroom experiences?

The findings from the TAIQ are particularly interesting in view of the comments made by Percy-Smith *et al.* (2008) where the authors concluded that caregivers' opinion that their children had a quality of life as good as or even better than that of hearing peers, should be considered as valid, because their later published findings from a related study (Percy-Smith, 2009) indicated that caregivers were "valid reporters of the level of their children's auditory, as well as speech and language development" (p. 50). Based on comparison of self- versus caregiver-ratings on the TAIQ, SAC-A and SOAC-A in the present study, we propose that caregiver perspectives do not reflect the adolescents' perspectives equally well on all aspects of performance.

This study was the first of its kind in India to include such a large number of centers representing a diverse recipient group from across the country. The participants were from different linguistic, cultural, and economic backgrounds. Further, the study investigated a less-explored area in long-term outcomes of CI. However, it was not without limitations. No conventional markers of performance such as measures of speech-language levels or speech perception were included. These were not undertaken due to feasibility issues. The data that had to be collected as part of this study already involved significant time per participant. Another source of variability which could not be completely controlled was the mode of administering the questionnaires. We had to accept responses in all forms: through interview mode, some filled out at the center by the AWCI and their

caregivers; some taken home to complete and return; and a few returned via email. We also included all adolescents with prelingual hearing loss irrespective of congenital, acquired, or progressive hearing loss. Device configuration (unilateral CI, bilateral CI and bimodal) and extent of pre-CI aided benefit were also not considered as independent variables for data analysis.

The above mentioned aspects could be taken into consideration in future studies. In general the factors that affect outcomes from CI are numerous and difficult to control or account for within a single study. Despite its limitations, the present study highlighted some important points that warrant further research and discussed areas in which intervention could be strengthened.

Conclusion

Our findings indicated that caregiver judgments of their adolescents with CI were not in equal agreement with self-ratings by the adolescents across various aspects of performance. Caregivers appeared to underestimate the issues faced by adolescents with CI in areas such as athletic competence, conduct/morality, peer acceptance, physical appearance, and scholastic competence as represented by the TAIQ but had excellent agreement with their adolescents' self-rating of communication success. Our study showed a significant association (correlation) between peer acceptance and athletic competence. Hence we propose that the inclusion of activities specifically designed to improve children's participation in sports, and counseling caregivers about the importance of play and sports are important. Games and sports provide excellent opportunity for establishing peer relationships and for learning to cope with social situations.

Age at CI, implant age, and chronological age did not show a definite trend of associations with self- or caregiver-ratings on the tools used for the present study. These findings do prompt the need for research into the long-term effect of age at CI on a wider range of skill sets. Which skill sets are most and least affected by age at CI? Also, do some skills show delay in the initial years post CI, but get increasingly compensated for in the long term? Future studies on adults with prelingual hearing loss who received CI at different ages would undoubtedly shed more light on these aspects.

With reference to the difference between adolescent and caregiver ratings, two interesting questions to ask would be: 'where does the truth lie?' and 'what should be the gold standard for gauging performance: self-ratings or significant-other-ratings?' Irrespective of what the answer to these might be, it is clear that we cannot restrict ourselves to traditional tests to measure outcomes from CI in the long-term.

Professional teams need to develop ways to strengthen the support network for individuals with CI to address issues other than the core areas of auditory, speech, and language performance. A follow-up of this study a few years later, if feasible, would be valuable in understanding whether a similar profile is obtained when these adolescents grow into young adults. Hence professionals working in this area of (re)habilitation of individuals with CI do have a lot to ‘think about’.

Disclaimer statements

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Funding None.

Conflict of interest None.

Ethics approval was taken from an Independent Institutional Ethics Committee.

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