A comparison of the quality of life of parents of children using hearing aids and those using cochlear implants

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2. Introduction

The Joint Committee on Infant Hearing (JCIH) recently introduced the 1-2-3 target for newborn hearing detection and intervention programs in its latest Position Statement in 2019. According to these guidelines, all infants should be screened for hearing loss by one month, diagnosed by two, and rehabilitation initiated by three months of age (Journal of Early Hearing Detection and Intervention, 2019). The benefits afforded by such early diagnosis and intervention for linguistic, social, and academic development appear to be significant (Papacharalampous et al., 2011; Wroblewska-Seniuk et al., 2017). The diagnosis of hearing loss in an infant, on the other hand, is a time of crisis for most parents, and may be accompanied by feelings of grief, anger, and helplessness (Mellon, 2009). Grief, such as that of death, consists of certain stages – denial, anger, bargaining, depression, and acceptance. The grief may terminate after individuals pass through each or some of these stages. However, in living with a disability such as hearing loss, the grief may be chronic (Bruce and Schultz, 2001). The issue of chronic parental grief and related coping mechanisms has not been the subject of much attention (Kurtzer-White and Luterman, 2003). Furthermore, children with hearing loss are frequently born into households who have never dealt with the condition before (Schein and Delk, 1974). Hence, while an early diagnosis of hearing loss is beneficial in the long run, it also puts a great deal of pressure on the caregivers. Families that are already attempting to manage the emotional consequences of hearing loss in their newborn must also quickly move on to decide on their child’s future (Decker et al., 2012; Matthijs et al., 2012) with relatively limited knowledge and preparedness. The hearing professional must be cognizant of this fact, and take measures to equip parents better to cope with the impact of their child’s hearing impairment.

The initial interactions between the parent and child and their
bonding are intimately linked to the emotional development/state of the infant and parent. The disruption caused in this period due to hearing loss diagnosis and intervention process may negatively affect the mother-child bonding and the maternal psyche. It has been evidenced in the literature that a reduced age of diagnosis can potentially increase parental stress (Konstantareas and Lampropoulou, 1995). However, increased psychological distress has been reported in parents of children intervened later in life, possibly due to communication difficulties that may arise between the parents and the child (Zaidman-Zait, 2008).

Exacerbating parental difficulty is the communicative, behavioral and social consequences of childhood hearing impairment. Children with hearing impairment tend to have lower verbal output relative to their normal-hearing peers. Thus, the communication between the caregiver and the child may be poorly established, creating frustration for both parties (Freeman, 2000; Zaidman-Zait, 2008). Children with hearing impairment are also more prone to behavioral issues than their normal-hearing counterparts. Studies suggest that behavioral problems and bad temperament of the child may create or increase stress for the parents (Sarant and Garrard, 2014; Watson et al., 1990; Wiseman et al., 2021), on occasion even more than the speech and language impairment itself (Limm and von Suchodoletz, 1998). Hearing impairment may also cause the child to fall behind their hearing peers in psychosocial development and social skills. Any disability, in general, can result in an increase in parental psychological distress. (Dyson, 1993; Hadadian, 1994). The presence of hearing impairment in a child may thus act as a significant stressor for parents.

Early diagnosis and prompt fitting of hearing aids (HA) or cochlear implants (CI) followed by intensive therapy are needed to propel linguistic, emotional, and social development for the child with hearing impairment. However, it should not be forgotten that the parents are the professionals' indispensable partners in fostering these skills, and their cooperation in the rehabilitation process is of utmost importance. Importantly, parental distress may have direct and deleterious consequences on the child's development, and this may decelerate the progress made in intensive rehabilitation efforts. It has been shown that highly stressed mothers are less attuned to the infant's needs, thereby affecting their socioemotional development (Crnic et al., 1983). Maternal sensitivity and the mothers' communication style facilitate and incentivizes language acquisition in young children with hearing impairment (Pressman et al., 1999).

Over the years, quality of life has become a more accepted measure of the impact of various diseases on a persons' wellbeing. Quality of life (QoL) measures are more multidimensional than the single measure of psychological stress. Several studies have looked at the psychological distress of parents of children with hearing impairment. It may be argued that since cochlear implantees tend to have superior auditory perception than their HA counterparts (Ashori, 2020) and since communication abilities determine parental stress, at least in part, CIs may result in reduced parental stress compared to HA. Several studies have looked at the psychological distress of parents of CI users and have concluded that, on the whole, these parents are more susceptible to increased psychological stress than parents of children without a hearing loss (Quittner et al., 1991; Sarant and Garrard, 2014). Parental stress is increased during the time of diagnosis (Burger et al., 2008; Spahn et al., 2003, 2004), and it persisted across the period of rehabilitation at least about a quarter of the parents sampled (Richter et al., 2000). Whether or not to go ahead with a CI was also cited as a cause of stress (Li et al., 2004), as was the actual fitting process (Spahn et al., 2003). Similarly, Parental Stress Index (PSI) scores increased over time for parents of CI users (Purdy et al., 1995). For children using HAs, parental stress has been evidenced to be higher than the norm (Watson et al., 1990). When intervention options are compared, Horsch et al. in 1997 have noted that parents of CI users experience stress at levels similar to those of parents of normal-hearing children and that parents of HA children suffer from the most stress (Horsch et al., 1997). Maternal overall health was better when the hearing-impaired child was intervened with CI than HA (Gohari et al., 2020). However, in another study, parents of children receiving HA experienced lower stress and anxiety levels than those receiving CI. However, the condition of both these groups of parents was worse than those parents who had normal-hearing children (Mahmudi et al., 2017). More distress on the parents of CI compared to HA users was found when the family climate was considered (Spahn et al., 2003).

Studies have found that the psychological condition of the mothers at the time of diagnosis and CI activation was significantly correlated to the child's linguistic and communicative development post CI fitting (Majorano et al., 2020). Therefore, ameliorating the parents' psychological distress may improve child outcomes. Spahn et al. (2001) has shown that caregivers of children with hearing loss demonstrate both high-stress levels and high motivation to utilize psychosocial support measures. It has also been established that parents of children with HA and CI can be considered as two distinct groups based on psychosocial parameters and support required (Spahn et al., 2003). Thus, determining the levels of stress and the specific domains of support needed can help further rehabilitation efforts for children with hearing impairment.

In developing countries like India, Universal Newborn Hearing Screening (UNHS) has not yet been fully achieved due to the paucity of the workforce, financial resources, and public awareness (Galhotra and Sahu, 2019; McPherson, 2012; Olusanya et al., 2004). In many cases, the diagnosis of hearing loss may not occur until the child is at least two years of age. In addition to the delay in initiating rehabilitative services for children, parents as an at-risk group have also been somewhat overlooked. Studies comparing parental stress of children with hearing aids and CI has been scarce. Prakash et al. (2013) have found that parents of children with CI and those using HA were both highly stressed but with greater stress levels in the CI group. The time of diagnosis of hearing loss is stress-inducing, and the condition did not change significantly with hearing aids. However, CI fitting dramatically decreased stress levels (Dev et al., 2018). The present study thus focused on the Indian scenario and aimed to look at the quality of life of parents of children fitted with HA and CI and document any differences between both groups. Any such difference would be in line with Spahn et al. (2001)'s conclusion that both these parental groups may benefit from distinct counseling and support measures tailored to the intervention of choice.

3. Materials and methods

3.1. Study design and sample

The present study employed a cross-sectional design to collect data from parents of children with hearing aids (HA) and cochlear implants (CI) receiving listening training services at the All India Institute of Speech and Hearing (AIISH), Mysuru, Karnataka. The Government of India provides hearing aids and CIs at subsidized rates through several schemes for clients depending on their financial ability, and CIs are provided free of cost for those below the poverty line. Listening training, speech therapy, and special school services were provided at AIISH at subsidized rates for both groups, also depending on the financial status. Convenience sampling was used and no specific inclusion or exclusion criteria were
imposed; instead, all clients were encouraged to participate in the study. All participants were native speakers of Kannada and proficient in reading and writing the language according to self-report. One hundred thirty-one parents (87 HA and 44 CI) were contacted personally through telephone and asked to fill in a Google Form sent to them electronically. Out of them, 49 (29 HA and 20 CI) parents responded (return rate 33.3% for HA and 45.4% for the CI), a proportion not uncommon for surveys of the kind (Spahn et al., 2003). Only one parent per child was sent the form, depending on the respondent to the telephone call. The form contained queries related to the child’s sociodemographic details and the Kannada-language version of the Assessment of Quality of Life – 4 Dimensions (AQoL-4D) questionnaire. All children with CI were unilaterally implanted, and all except one participant had received the device through Government schemes at subsidized rates. This may act to potentially nullify any additional financial stress the CI group may face over the HA group for our sample. All children in the HA group were bilaterally fitted. The study was approved by the Institutional Review Board of the All India Institute of Speech and Hearing. All participants provided written informed consent.

3.2. Sociodemographic details

A non-standardized format was employed in the electronically disseminated Google Form link to collect sociodemographic information. The data about type and degree of hearing loss, age of identification of hearing loss, and age at intervention were extracted from the institute record after the response was collected. None of the children included in the study were diagnosed with any condition associated/comorbid with hearing loss.

3.3. The AQoL-4D (Kannada version)

The Kannada version of the Assessment of Quality of Life – 4 Dimensions (AQoL-4D) was translated in 2016 (Thammaiah et al., 2016) and validated in 2019 (Thammaiah et al., 2019) for use in the Kannada-speaking adult population with hearing loss. The original English version of the scale could be used as both a psychometric and a utility measure, and the four domains covered independent living, social relationships, physical sense, and psychological wellbeing. The Kannada version was validated as a psychometric measure and consisted of 12 questions divided into four domains (social relationships, interaction and mental state; physical wellbeing; self-reliance during daily activities; and sight and sleep). The tool helps gauge the influence of hearing loss in everyday life situations for the person with hearing impairment.

For the purposes of this study, we have modified the administration of the questionnaire so that it can be used to estimate the quality of life of the adult whose child is affected by hearing loss. Specifically, the parents were asked to rate each question keeping in mind the impact of their child’s hearing loss on their quality of life, rather than their own hearing issues. The parents were instructed to fill out the forms sent to them and were not assisted in any manner other than by clarifying the instructions. It may be that since the tool has not been validated in parents of children with hearing impairment, the usage of the same in this study may be considered as a non-standardized and fairly qualitative measure of QoL. As a preliminary analysis of parental distress in HA versus CI fitting, these results may still provide insight into parents’ QoL. The scoring for the psychometric version of the Kannada translation of the AQoL-4D is a simple unweighted sum of the scores of questions pertaining to each domain. It has been recommended by the authors that either the first subscale or the entire questionnaire be used, citing high internal consistency of the same (Thammaiah et al., 2019). The responses collected were transferred into a Microsoft Excel document, and domain scores were calculated. Statistical analysis was carried out in the IBM SPSS Statistics 25.0 software.

4. Results

The sociodemographic and intervention-related details collected are presented in Table 1. The mean total scores for the hearing aid (HA) group was 17.9 (SD = 5.5), and for subscale 1 it was 8.6 (SD = 2.9); the same for the cochlear implant (CI) group were similar, being 17.2 (SD = 3.4) and 8.5 (SD = 2.6), respectively, as shown in Table 2.

The Shapiro-Wilk test was conducted to test for normality, and it was found that both the total score and Subscale 1 score followed a non-normal distribution (p < 0.05). Accordingly, non-parametric analysis was carried out on the data. The Mann Whitney U test was performed to compare the HA and CI groups for the total and the Subscale 1 scores, represented in Table 3. No significant differences were found between the two groups on either parameter [Total Score: U (NHA = 29, NCI = 20) = 280.5, z = -0.194, p > 0.05; Subscale 1 Score: U (NHA = 29, NCI = 20) = 281.5, z = -0.176, p > 0.05].

To see if there was any difference in the distribution of the chronological age, age of intervention, and duration of intervention for the intervention technique used, Independent Samples Mann Whitney U Test was further carried out. The results revealed that, while the duration of intervention was not significantly different (p > 0.05), the distribution of chronological age, as well as the age of intervention, was found to be significantly different across the HA and CI groups (p < 0.05). Indeed, the members of the HA group were younger (Mean = 55.2 months, SD = 25.5) than those of the CI group (Mean = 67.6 months, SD = 12.3). Age of intervention was also lower for the HA group (Mean = 34.3 months, SD = 23.1) than the CI group (47.5 months, SD = 12.8).

The degree of hearing loss may be expected to be different for the two groups. Qualitatively, it was noted that most members of both the HA and CI groups had profound hearing loss. Three HA group members had moderately severe hearing loss, and one had a moderate loss, while all members of the CI group had profound hearing loss.

Spearman’s rank-order correlation was done to see if there was any correlation between the parameters under study, which revealed several significant correlations, as shown in Table 4. A strong positive correlation was found between the chronological age and the amplification strategy (p < 0.01), age of intervention and chronological age (p < 0.01), moderate positive correlation between duration of intervention and chronological age, amplification option, and age of intervention (p < 0.01) and weak positive correlation between chronological age and amplification option (p < 0.05). A very strong positive correlation was seen between the total and subscale 1 scores (p < 0.01).

5. Discussion

The present study was a preliminary effort to look into the quality of life (QoL) of parents of children with hearing aids (HA) and cochlear implants (CI) in India. The literature on parental distress concerning children using different amplification options has been inconsistent. This study has qualitatively concluded that the chosen intervention option does not determine the parents’ QoL. Both HA and CI afforded remarkably similar AQoL-4D scores, which were on the lower end of the norm, indicating a fairly good QoL for both groups. Of note, the score of the first subscale is similar for both the groups, meaning that these parents perceive social relationships, interaction, and mental state in a similar manner.
These domains are greatly affected for individuals with hearing impairment (Thammaiah et al., 2019), and it may be that these areas are also highly relevant for individuals whose children are affected by the same. Notably, the Kannada translation of the AQoL-4D contains more questions in this subscale than the others (six in Subscale 1 versus two each in the other three subscales). The strong positive correlation noted between the total scores and the Subscale 1 scores may also be attributed to the fact that Subscale 1 by itself comprises half the questions of the Kannada translation of the AQoL-4D.

Since most of the children in our sample had severe-to-profound hearing loss, the CI may be expected to be a better amplification option as compared to high-gain HAs. Since it has been evidenced that parents view the CI as providing better communication skills than other aids, and communication skills may be a factor that significantly affects parental psyche (Soleimanifar et al., 2015), it might have resulted in reduced parental stress. However, this was not observed in our study.

| Table 1 | Sociodemographic data across the HA and CI groups. |
| --- | --- |
| **Amplification Strategy** | **Age** | **Gender** | **Age of intervention** | **Duration of intervention** |
| **HA** | Mean | 55.24 | Males – 20; Females – 9 | 34.35 | 20.90 |
| | N | 29 | 29 | 29 | 29 |
| | Std. Deviation | 25.49 | 23.13 | 14.45 |
| **CI** | Mean | 67.60 | Males – 10; Females – 10 | 47.50 | 20.10 |
| | N | 20 | 20 | 20 | 20 |
| | Std. Deviation | 12.33 | 12.84 | 10.29 |
| **Total** | Mean | 60.29 | 39.71 | 20.57 |
| | N | 49 | 49 | 49 | 49 |
| | Std. Deviation | 21.84 | 20.43 | 12.81 |

| Table 2 | Total and Subscale 1 scores of the AQoL-4D across the HA and CI groups. |
| --- | --- |
| **Total Score** | **Subscale 1 Score** |
| **HA** | Mean | 17.86 | 8.62 |
| | N | 29 | 29 |
| | Std. Deviation | 5.50 | 2.92 |
| **CI** | Mean | 17.20 | 8.50 |
| | N | 49 | 49 |
| | Std. Deviation | 3.37 | 2.63 |
| **Total** | Mean | 17.59 | 8.57 |
| | N | 49 | 49 |
| | Std. Deviation | 4.72 | 2.78 |

| Table 3 | Results of tests of significance across the HA and CI group for total score on the AQoL-4D. |
| --- | --- |
| Mann-Whitney U | 280.50 |
| Wilcoxon W | 490.50 |
| Z | 0.194 |
| Asymp. Sig. (2-tailed) | 0.84 |

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| Table 4 | Results of tests of correlation for the HA and CI groups across different parameters. |
| --- | --- |
| **Age** | **Gender** | **Amplification** | **Total Score** | **Subscale 1 Score** | **Age of Intervention** | **Duration of Intervention** |
| Pearson Correlation | 1 | 0.05 | 0.28 | –0.01 | –0.06 | 0.82<sup>a</sup> | 0.40<sup>b</sup> |
| Sig. (2-tailed) | 0.73 | 0.05 | 0.91 | 0.68 | 0.00 | 0.01 |
| N | 49 | 49 | 49 | 49 | 49 | 49 |
| **Gender** | Pearson Correlation | 0.05 | 1 | 0.19 | –0.24 | –0.17 | 0.04 | 0.02 |
| Sig. (2-tailed) | 0.73 | 0.19 | 0.10 | 0.26 | 0.78 | 0.87 |
| N | 49 | 49 | 49 | 49 | 49 | 49 |
| **Amplification** | Pearson Correlation | 0.28 | 0.19 | 1 | –0.07 | –0.02 | 0.33<sup>b</sup> | –0.03 |
| Sig. (2-tailed) | 0.05 | 0.19 | 0.63 | 0.88 | 0.03 | 0.83 |
| N | 49 | 49 | 49 | 49 | 49 | 49 |
| **Total Score** | Pearson Correlation | –0.02 | –0.24 | –0.07 | 1 | 0.85<sup>a</sup> | –0.04 | 0.04 |
| Sig. (2-tailed) | 0.73 | 0.05 | 0.91 | 0.00 | 0.00 | 0.00 |
| N | 49 | 49 | 49 | 49 | 49 | 49 |
| **Sub 1 score** | Pearson Correlation | –0.06 | –0.17 | –0.02 | 0.85<sup>a</sup> | 1 | –0.03 | –0.06 |
| Sig. (2-tailed) | 0.68 | 0.27 | 0.88 | 0.00 | 0.00 | 0.00 |
| N | 49 | 49 | 49 | 49 | 49 | 49 |
| **Age of intervention** | Pearson Correlation | 0.04<sup>a</sup> | 0.04 | 0.32<sup>b</sup> | –0.04 | –0.03 | 1 | –0.20 |
| Sig. (2-tailed) | 0.73 | 0.03 | 0.77 | 0.85 | 0.16 |
| N | 49 | 49 | 49 | 49 | 49 | 49 |
| **Duration of intervention** | Pearson Correlation | 0.40<sup>a</sup> | 0.02 | –0.03 | 0.04 | –0.06 | –0.20 | 1 |
| Sig. (2-tailed) | 0.73 | 0.03 | 0.77 | 0.85 | 0.16 |
| N | 49 | 49 | 49 | 49 | 49 | 49 |

<sup>a</sup> Correlation is significant at the 0.01 level (2-tailed).
<sup>b</sup> Correlation is significant at the 0.05 level (2-tailed).
equivalence in QoL scores of the HA and CI groups contrasts with previous studies that noted differential parental stress levels when managed with one device compared to the other. Horsch et al. (1997) had concluded that parents of HA users suffered from more stress than those with CI (Horsch et al., 1997), and this finding has been substantiated by other studies as well (Hashemi and Monshizadeh, 2015; Prakash et al., 2013). The general health of the mothers of CI users has been reported to be significantly better than that of the mothers of children with HAs (Gohari et al., 2020). However, Prakash et al. (2013) have noted that both groups might suffer from equal stress that applies to certain domains of life (Prakash et al., 2013). Burger et al. (2006) have also come to similar conclusions, finding that although their sample of parents of children with HA and CI had an affected QoL initially, enduring parental distress was not present (Burger et al., 2006).

Several reasons may account for the findings of this study. Since all participants in the study could avail devices and services according to their financial capabilities, we may hypothesize that this was not the factor responsible for the finding of no significant difference between the HA and CI groups in terms of quality of life. The stress experienced by the parents may also vary with the time point they are passing through in the rehabilitative process. It has been evidenced that parents suffer from most stress at the diagnosis stage (Dev et al., 2018; Hintermair and Horsch, 1998; Richter et al., 2000), and during the surgery for CI (Dev et al., 2018). Stress levels tend to stabilize at later points in time (Burger et al., 2005, 2008). The mean duration of intervention was about 20 months for both groups in our sample. It is thus likely that the stages of highest stress have passed and might explain the enhanced QoL noted in both groups.

Another factor may be the age of the children in both groups. Generally, children with HAs can be thought to have milder losses than those with a CI. Notably, our HA Group predominantly exhibited a degree of loss as high as the CI Group (severe to profound), yet similar scores were achieved for both groups regardless of the management option. This may imply that, to the extent that they mitigated parental stress levels and functional ability, hearing aids were at least as effective a treatment option for hearing loss as CI. Indeed, most HA Group scored 1, indicating best health, for most questions on the scale, as did most of the CI Group. This may be due, in part, to the fact that the HA users in our sample were intervened at a mean age of 34.3 ± 23.1 months - within the critical period for language acquisition. Diagnosis at a young age can result in greater levels of parental stress since it may result in less than adequate bonding between the parent and the infant (Bess and Paradise, 1994). However, this was not noted in the present study; instead, our findings support the notion that early identification of hearing loss can have tremendous benefits for children’s linguistic abilities (Yoshinaga-Itano et al., 1998) and the psyche of the parents. Auditory Verbal Therapy initiated around this period being strongly correlated with improved communication abilities (FSPAA et al., 2009; Hickson et al., 2010); years of therapy may have culminated in similar communication levels for both groups of children.

It is possible that, while rehabilitation within the critical period has helped maintain the QoL of the parents of both groups, an additional advantage for the CI group might have been that they were older than those of the HA group. The age disparity is likely because the CI was fitted only after a trial with HAs. This might also explain the reduction in the age of intervention in the HA group compared to the CI group, the strong correlation found between the chronological age and amplification strategy, and the moderate correlation between the CI group age of intervention and amplification option. The benefit with CI has been stated to be an adaptive phenomenon, and parental QoL and time since intervention with a CI has been found to be significantly correlated (Spahn et al., 2004).

This is supported by studies on the long-term effects of CI (Waltzman et al., 2002).

The technology used in the CI may also have implications for stress levels in parents. A study by Quittner et al., in 1991 found that the parents of users of multichannel CI appeared to be more stressed than users of single-channel CI (Quittner et al., 1991). It has also been evidenced that present generation CI technology decreased stress levels compared to older technology (Wiseman et al., 2021). We have not looked into the specifications of the devices worn by our sample of children, but it may be speculated that the improvement in technology since Quittner et al.’s study in 1991 may have facilitated the improvement noted in QoL measures. Parental expectation may serve as an important mediator of psychological distress. Given the success of the cochlear implant in children and the rapid development of speech and language skills witnessed in its users in the years following implantation, the expectation of the parents of CI children may increase with time (Richter et al., 2000) and act to mitigate the stress levels following the surgery. It has also been noted that parental expectations tend to increase with time in the CI group (Richter et al., 2000) and that a positive outlook for CI may help lessen stress (Bashiri et al., 2020). Furthermore, Weisel et al. (2007) observed that parents of children who were deaf and those of children who had CI did not suffer from heightened stress due to the positive attitudes toward the implantation and its outcomes (Weisel et al., 2007).

Increased parental stress has a significant and negative impact on the child’s development (Saran and Garrard, 2014). Majorano et al. (2020) have noted the deleterious effect parental distress may have on the linguistic and communicative development of the child with CI (Majorano et al., 2020). Along with prompt diagnosis and intervention, the JCIH also encourages family partnership in managing children with hearing impairment (Journal of Early Hearing Detection and Intervention, 2019). Recognizing the advantages of Family Centred Care and the importance of parental involvement and wellbeing as being critical to the family as well as the child, the parents of children with hearing impairment must be provided supportive measures in the form of informational resources as well as emotional support to assist them in understanding hearing impairment and in enhancing family competence to manage the same. It is significant to note that a good proportion of parents of both CI children are suffering from great psychological stress and demonstrate an interest in psychosocial support measures, such as more information on sources of assistance for their children and parental support groups (Spahn et al., 2001). Along with the goal of universal newborn hearing screening, India must also target services for the parent of children with hearing impairment since they are a vulnerable group in and of themselves.

6. Conclusion

Our sample of parents of children with hearing aids and cochlear implants appears to be similar on various psychosocial aspects in functional, social, and psychological wellbeing. Insofar as the parental quality of life is concerned, hearing aids and cochlear implants appear to be equally effective intervention strategies for children with hearing impairment. The parents of such children must also be provided services to help them cope better with the emotional consequences of hearing loss in their child.

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Ethical approval
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Informed consent
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Declaration of competing interest
The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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