International Journal of Otorhinolaryngology and Head and Neck Surgery
*Chowdhary S et al. Int J Otorhinolaryngol Head Neck Surg. 2026 Aug;12(4):xxx-xxx*
https://www.ijorl.com
pISSN 2454-5929 | eISSN 2454-5937

DOI: https://dx.doi.org/10.18203/issn.2454-5929.ijohns20261853

**Original Research Article**

# Caregiver burden in primary caregivers of pediatric cochlear implantees: a cross-sectional study from a tertiary referral centre in Southern India

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**Received:** 15 May 2026
**Revised:** 04 June 2026
**Accepted:** 06 June 2026

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## ABSTRACT

**Background:** Caregiving for paediatric cochlear implantees (CI) is challenging, underreported and has not been quantified. This study has implications for improving support systems for the primary caregivers of paediatric cochlear implantees.

**Methods:** The analysis was done using the Zarit burden inventory (ZBI), the Oh and Seo family caregiver burden scale (FCBS) and the Pai and Kapur family burden interview schedule (FBIS), and the burden of care was correlated with socio- economic-demographic factors. 119 implanted children during the period 2018-2025 and their caregivers were recruited. All patients had undergone at least three months of auditory-verbal rehabilitation therapy (AVT).

**Results:** The mean age at implantation was 3years. All the primary caregivers were female. 83% of the primary caregivers were the mothers of the implantees. 21.8% of the respondents had additional responsibility in the form of another sick person at home. The mean duration of AVT was 11.94 months. The mean distance of the AVT centre from the patients' homes was 42 km. The age of CI was statistically significant for financial burden in the FCBS. The distance of the AVT centre contributed to a statistically significant emotional burden. Caregiving was significantly easier for children for whom at least 3 years had elapsed since surgery. The ZBI screening tool correlated well with the FCBS and the FBIS for documenting burden.

**Conclusions:** Caregivers burden (CB) is significant economically and when it involves younger children, recent surgery and travel for AVT. Women bear all caregiving responsibilities at home. The ZBI can be used as a rapid screening tool for CB.

**Keywords:** Cochlear implant, Caregiver burden, Economic burden, Quality of life, Paediatric cochlear implantation, Financial burden

## INTRODUCTION

Caregiver burden (CB) refers to the physical, emotional, and financial strain experienced by individuals who care for family members or loved ones with chronic illnesses or disabilities.[1] In the context of paediatric cochlear implantees (CI), primary caregivers often assume responsibilities such as managing their child's device, facilitating communication, and coordinating medical appointments and rehabilitation services. When compounded by the postoperative course of a major surgery with the needs of a child, the burden is significant and needs study.

Primary caregivers of children with CI experience elevated levels of stress, anxiety, and depression. Assessing CB is crucial for several reasons, primarily because it affects the caregiver's well- being and, in turn, impacts the quality of care. The constant need to monitor and manage their child's device, and the emotional demands of supporting a child with a disability, can take a profound toll on caregivers' physical and mental health. The financial burden of CI, including device costs, surgical expenses, and ongoing rehabilitation services, can exacerbate caregivers' stress and anxiety. Despite the critical role that primary caregivers play in supporting children with cochlear implants, there is a paucity of research examining the CB in this population.[2] Understanding the scope and nature of CB is essential for developing targeted interventions and support services that can mitigate the negative impacts of caregiving on physical and mental health. The term ‘caregiving burden’ originally came about for caregivers of chronically physically ill and mentally ill individuals.[3] It is also evident that the CB increases even further if they are underprivileged with limited resources and/or are in poor health. Various tools are available that can be used to measure CB, such as the Zarit burden interview (ZBI), the caregiver self-assessment questionnaire (CSQ), the caregiver burden inventory (CBI), and the caregiver reaction assessment scale (CRAS), among others.[4-7] There are studies that have assessed the impact of CI on the QOL of children; however, there are insufficient studies of the burden on primary caregivers of children who underwent CI for congenital SNHL.

The objective of the study was to quantify the caregiver burden in social, financial and emotional domains using standard validated Oh and Pai questionnaires for assessing caregiver burden and correlate the Zarit screening tool with the other established questionnaires to assess caregiver burden. The primary outcomes of the study were CB and the correlates of caregiver burden (e.g., child's age, additional disabilities, family dynamics).

## METHODS

This study investigated the CB in social, financial and emotional domains for the primary caregivers of paediatric CI using standard validated Oh and Pai questionnaires for assessing CB and correlating it with the modified Zarit Burden Inventory. Other correlates of CB such as child’s age, other caregiving responsibilities and economic factors were also studied. This was a cross-sectional study carried out from February to July 2025 in the paediatric ENT unit of Christian Medical College, Vellore, Tamil Nadu, with consecutive sampling of patients and their caregivers. Institutional Review Board approval was obtained (IRB Min. No 2502001, dated 12.02.2025). Both face-to-face and tele-video-consultation were employed. Considering a mean prevalence of 30% with a precision level of 5% and a confidence level of 95% (1-alpha error), the calculated sample size was 126 participants. However, only 119 patients could be recruited for the study.

A primary caregiver was identified as the one primarily involved in taking care of the child at home and spending maximum time in caring for the child’s needs. Reliable caregivers were considered as the ones who actually participated in the care of the child and carried the majority of the burden. Adult implantees, non-users and implants done as revision and for post lingual hearing losses were not included in the study. The family caregiver burden scale (FCBS), family burden interview schedule (FBIS) and the ZBI were administered to the caregivers and responses were recorded. A total of 119 patients and their caregivers were included in the study. The duration of CI and AVT taken was measured in months. Spearman’s rank correlation test was used to find the association between the categorical variables. All the analysis was done using statistical package for the social sciences (SPSS) 21.0.

## RESULTS

Out of 119 patients, 67 caregivers were recruited face to face and 52 were recruited via tele-video-consultation. The mean age of the group which required caregiving was 3 years, with a range of 1-17 years. All primary caregivers were females. 83% of the primary caregivers were mothers of the implanted children. 70 children were male. 96 children were implanted on the right ear, 16 on the left and 7 were implanted bilaterally. There was no correlation of CB with the gender of the child and the side of implantation. All children with their caregivers had undergone at least 3 months of postoperative AVT at our hospital itself. The mean duration of postoperative AVT taken elsewhere was 11.95 months, with a range of 0-84 months (Table 1).

**Table 1: Duration of additional AVT taken in months, over and above 3months of AVT at the surgery center.**

| Duration of additional AVT (months) | Number of patients’ caregivers |
|---|---|
| **0** | 21 |
| **1** | 2 |
| **2** | 4 |
| **3** | 4 |
| **5** | 5 |
| **6** | 16 |
| **7** | 4 |
| **8** | 4 |
| **9** | 2 |
| **10-12** | 20 |
| **14-18** | 15 |
| **20-28** | 11 |
| **>36** | 9 |

The mean distance of the AVT center from the home of the caregivers and the cochlear implantees was 42 km, with a range of 0-200 km. A higher distance from the home was associated with significant caregiver burden 8. Due to travel expenses and need to make other necessary changes, the distance of the AVT centre from home contributed to a significant caregiver burden (Table 2).

Comorbidities in other members of the family contributed to significant social and emotional burden, with caregivers having to care for multiple sick family-members at the same time. 26 of 119 had another sick member in the family needing caregiving.

**Table 2: Distance travelled for additional AVT with respect to the number of caregivers.**

| Distance travelled (km) | Number of patients' caregivers |
|---|---|
| **0** | 6 |
| **2-7** | 11 |
| **10-15** | 21 |
| **20-60** | 48 |
| **70-100** | 12 |
| **>150** | 6 |

The Oh and Seo FCBS for chronic illnesses was used as a complete questionnaire with multiple domains: physical, social, emotional and financial.[9] The caregiver responses were graded as mild-1, moderate- 2, severe-3 and very severe-4 on a Likert scale. It is a 27-item questionnaire which was validated in Korea for assessing caregiver burden in chronic patients. The Pai and Kapur FBIS was used to record CB. It is a 24-item questionnaire used to record financial, social and interpersonal conflicts during caregiving.[10] It was graded as no burden-0, minimal burden-1 and severe burden-2.

The ZBI is a 29-item validated tool for CB, however, the abbreviated Zarit screening tool with 4 items was used in this study.[11] The correlation of caregiver burden with the age at the implant in years using Spearman's rank correlation is mentioned in Table 3.

It was hypothesized that a younger implanted child posed greater challenges, and a positive correlation is expected.[12] The age-specific burden of caregiving was calculated using ANOVA test and the results are in Table 4. The correlation with the distance of the AVT center from home is mentioned in Table 5.

**Table 3: Correlation of CB from three questionnaires with age at implant of the child.**

| Questionnaire and domain | | Correlation | P value |
|---|---|---|---|
| **ZBI** | | 0.04 | 0.6 |
| **Oh and Seo FCBS** | Physical | -0.13 | 0.1 |
| | Emotional | 0.11 | 0.22 |
| | Social | 0.003 | 0.96 |
| | Financial | 0.18 | 0.04 |
| **Pai and Kapur FBIS** | Financial | -0.008 | 0.93 |
| | Effect on family routine and leisure | -0.04 | 0.6 |
| | Effect on physical and mental health | -0.057 | 0.53 |

**Table 4: Correlation of age-specific burden of caregiving.**

| Age brackets/ questionnaires (years) | ZBI | Oh and Seo FCBS | | | | Pai and Kapur FBIS | | |
|---|---|---|---|---|---|---|---|---|
| | | **P** | **E** | **S** | **F** | **Fi** | **Fa** | **H** |
| **<2** | 0.03 | 0.03 | 0.35 | 0.42 | 0.01 | 0.01 | 0.5 | 0.3 |
| **2-4** | 0.65 | 0.6 | 0.22 | 0.99 | 0.05 | 0.02 | 0.33 | 0.9 |
| **5-7** | 0.1 | 0.32 | 0.61 | 0.3 | 0.72 | 0.8 | 0.4 | 0.4 |
| **8-12** | 0.78 | 0.33 | 0.99 | 0.08 | 0.7 | 0.1 | 0.7 | 0.76 |
| **>12** | 0.42 | 0.98 | 0.11 | 0.12 | 0.8 | 0.3 | 0.9 | 0.33 |

**Table 5: Correlation of the burden of the three questionnaires with distance of the AVT centre from the home of the patient.**

| Questionnaire and domain | | Correlation | P value |
|---|---|---|---|
| **ZBI** | | -0.06 | 0.5 |
| **Oh and Seo FCBS** | Physical | 0.012 | 0.8 |
| | Emotional | -0.22 | 0.02 |
| | Social | -0.08 | 0.3 |
| | Financial | -0.12 | 0.2 |
| **Pai and Kapur FBIS** | Financial | -0.31 | 0.001 |
| | Effect on family routine and leisure | -0.09 | 0.35 |
| | Effect on physical and mental health | -0.03 | 0.72 |

The caregivers were advised to also continue the AVT at a center close to their home to ensure continuity of care and improve patient speech outcomes. A positive correlation indicates a higher burden with increasing distance across all domains.

A significant burden is expected on the primary caregiver if there exists another sick/bedridden/dependent family member who equally needs care. The two sample t-test with equal variances was used to identify significance and the values are in Table 6.

The mean duration of caregiving was 43.35 months, with a standard deviation of 27.66 months. The maximum duration of caregiving was 94 months in this data set. The correlation between the total time of caregiving and the questionnaire burden responses was calculated using the independent t-test (Table 7).

The immediate postoperative burden is the highest in view of direct causes from stress of surgery and future anxiety regarding device usage. The burden is hypothesized to reduce as and when time passes.[13] An arbitrary period of 3 years was considered the cutoff in this case, with lower burdens seen after 3 years of the surgery, with the assumption that the child would have integrated well into society by then. The ANOVA test was used to derive p correlating duration of caregiving with the caregiver burden (Table 8). An overwhelming majority - 83% of the patients in the data set were being cared for by the mothers, who had significant burden of care. The burden was much higher in the effect on family and the effect on physical and mental health of the family members in the Pai and Kapur FBIS. There was no significant difference between the burdens as perceived in face-to-face and tele-video/audio consultations.

**Table 6: Correlation in each domain with the presence of another morbid patient at home needing care.**

| Questionnaire and domain | | Difference between the means of the two groups | P value |
|---|---|---|---|
| **ZBI** | | -0.66 | 0.4 |
| **Oh and Seo FCBS** | Physical | -0.51 | 0.62 |
| | Emotional | 0.9 | 0.5 |
| | Social | 1.4 | 0.3 |
| | Financial | 0.14 | 0.86 |
| **Pai and Kapur FBIS** | Financial | -0.47 | 0.45 |
| | Effect on family routine and leisure* | 0.41 | 0.67 |
| | Effect on physical and mental health* | -1.32 | 0.18 |

*Two sample Wilcoxon rank-sum test

**Table 7: Correlation of the burden of the three questionnaires with total duration of caregiving since CI.**

| Questionnaire domain | | Correlation | P value |
|---|---|---|---|
| **ZBI** | | -0.44 | 0.6 |
| **Oh and Seo FCBS** | Physical | -0.36 | 0.7 |
| | Emotional | -0.52 | 0.9 |
| | Social | -0.4 | 0.35 |
| | Financial | -0.29 | 0.01 |
| **Pai and Kapur FBIS** | Financial | -0.36 | 0.01 |
| | Effect on family routine and leisure | -0.43 | 0.29 |
| | Effect on physical and mental health | -0.36 | 0.45 |

**Table 8: Correlation of caregiver burden with total duration of postoperative caregiving.**

| Time duration after implant and number of patients | | ZBI | Oh and Seo FCBS | | | | Pai and Kapur FBIS | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | **P** | **E** | **S** | **F** | **Fi** | **Fa** | **H** |
| **1-3 months** | 7 | 0.03 | 0.17 | 0.02 | 0.4 | 0.03 | 0.03 | 0.45 | 0.22 |
| **3 months-1 year** | 16 | 0.47 | 0.58 | 0.05 | 0.11 | 0.01 | 0.9 | 0.12 | 0.79 |
| **1 year-4 years** | 31 | 0.39 | 0.09 | 0.8 | 0.45 | 0.9 | 0.22 | 0.6 | 0.2 |
| **>4 years** | 65 | 0.12 | 0.37 | 0.3 | 0.33 | 0.78 | 0.35 | 0.56 | 0.1 |

## DISCUSSION

This is a novel study carried out a tertiary referral center, focused on the burden of caregiving in CI. It is a significant mental and physical burden to come to terms with a hearing-impaired child. CB been best described in families who care for the chronically ill and bedridden patients, who need constant supervision and directed care.[1]

Pediatric and adult patients often have different caregiving needs. Family members are key to administering health care to other loved ones. As a clinician, the aspect of CB about postoperative device challenges, recurring cost of consumable components of the CI and issues regarding access to care are unique to cochlear implantees.[14] The gender of the child and the side of the implant did not have any effect on the caregiver burden in our study. CB while not directly correlated with the child's gender correlates with the caregiver's gender and the gender of the child when considering the context of gender-related expectations and societal roles. Female caregivers report higher stress because of more hours and tasks. Societal expectations and cultural norms contribute to the stress. 100% of the primary caregivers were women, whether it was the mother, grandmother or another female relative, such as an aunt or a female hired help.[15] There was no significant difference in the responses collected via both the modes.

This study also used a modified ZBI to correlate with the burden captured by the FCBS and the FBIS. A shorter questionnaire was thus able to replace the standard long-form of the questionnaire and gives comparable outcomes. It can be used as a screening tool with reliable precision. Since the ZBI consists of four questions from each of the domains assessed by the FCBS, it effectively captures the comparable information in a shorter span of time. The presence of another family member who needs time, attention, supervision and care also compromised the care given to paediatric cochlear implantees. The strain felt by caregivers is often multifaceted, and include health problems, such as weight loss, fatigue and sleep disturbances. Emotional distress and psychological stress are also common among carers. In terms of family function, numerous studies have illustrated that caregiver burden often causes alienation or deteriorates of family relationships.[16,17] This study included burden involving the physical and mental health of caregivers, however it was not found to be statistically significant.

In the absence of a structurally validated post-surgical questionnaire for carers of surgical patients, our study aimed to capture the burden of postoperative wound care. The majority of the parents and primary caregivers such as mothers reported that they felt underconfident and unsure of postsurgical wound care. They expressed doubts and misgivings regarding postoperative surgical complications, which in turn increased their burden and ability to care effectively for the children. The duration of time elapsed since surgery also played a vital role in our study, as those implanted recently expressed more burden with respect to device and processor care, as well as about recurring costs and future expenses. These doubts are specific to cochlear implantees, and significantly affect perception of care. This burden was particularly high and significant in the financial domain for both the FCBS and FBIS.

Caregiver burden, in essence, is not always static. The caregivers master various nursing skills, step by step over time and gradually adapt to the pressure brought by caring tasks. The caregiver burden in general showed a declining trend over time.[18] The parents also come to terms with the diagnosis and have an increased acceptance of the device usage over time. The commonest stress reaction reported by the caregivers in our study was a sense of overwhelming responsibility because of the high cost of the device. It was also associated with a sense of anxiety of device damage or loss. A thorough pre-operative counselling session is usually beneficial and helps to allay fears. In our setting, a provision of tele-video or audio consultation was also provided, which helps the carers to contact the AVT counsellors and surgeons at any point of time.

Our study analysed the relationship between the level of the burden associated with the distance of AVT centre from the home of the paediatric cochlear implantees. Transporting a patient in need to a centre delivering care which improves the quality of life is physically demanding. Travel time, waiting at the hospital and appointments take up a significant portion of a caregiver's day.[19] Repeated or prolonged exposure to these stressors can contribute to caregiver burnout, a state of emotional, physical, and mental exhaustion. Having a regular online evaluation for tele-AVT helps children to integrate better in society without the hassle of physical travel. The correlation between the distance of the AVT centre from home and the CB was statistically significant in our study. The pre- and perioperative preparation for cochlear implants needs to address these issues to improve the overall quality of the postoperative care. In addition to having an implanted surgical device, the age group involved in paediatric cochlear implantation has challenges of its own in caregiving. Due to the long-term care, the caregivers of patients with any type of chronic ill-health pay limited attention to their own state of health and often suffer from health problems, such as weight loss, fatigue and sleep disturbances. Emotional distress and psychological stress are also common among carers. In terms of family function, long term care disrupts caregivers schedule and lifestyle. In our study, this is captured well in the 27-item and 24-item questionnaire. Many caregivers in our study had not sought medical help for themselves, in spite of being overwhelmed and unwell themselves, though these results were not statistically significant. This signifies a significant gap in provision of support services. We, as surgeons, should look into this particular aspect of burden counselling during our preoperative workup.[20]

Cochlear implant is a very expensive surgery in our socio-economic context. The financial burden for caregivers of individuals with cochlear implants can be substantial, encompassing both direct and indirect costs related to the implant itself, ongoing care, and potential societal impacts. These costs can include the initial implant and surgery, post- operative care, ongoing therapy and rehabilitation, device maintenance, and potential long-term educational and social integration challenges. The surgical procedure are significant upfront expenses.[21] Comprehensive assessments are needed to determine candidacy and ensure the implant is appropriate. Inpatient stays for surgery and initial recovery can add to the costs. Ongoing cost includes follow-up appointments with audiologists, speech therapists, and other specialists, which is crucial for language and communication development. CI requires regular maintenance, including replacement of parts, batteries, and accessories. If both ears require implants, costs can double.

Children with CI may require specialized educational support, potentially increasing tuition fees and other educational expenses. Parents or caregivers may experience increased stress and time commitment, impacting their work and personal lives. Families may face emotional challenges and social adjustments related to the child's hearing loss and the need for ongoing care. Caregivers might need to reduce work hours or even stop working to provide care, leading to potential financial strain. Overall, families may need to spend a larger portion of their income on healthcare related to hearing loss. The financial burden can extend throughout the individual's lifetime, especially if they require ongoing support and rehabilitation. This study found a positive correlation of all parameters with financial burden. Almost every patient and their parents had to undergo some form of adjustment in finances in order to fund the surgery and were continuing to do so for the postoperative AVT. Support in the form of social schemes and insurance measures can help to some extent.

### *Strengths*

The study is novel in that there is lack of prior studies in the Indian context which has analyzed caregiver burden of parents of postoperative cochlear implant children. Very few studies have documented the burden associated with travel involved in obtaining care for the children. In addition to studies recruiting children with hearing loss, this study also looks at multiple domains across three questionnaires, which further confirms burden. A well-functioning follow-up protocol was used to ensure caregivers were recruited during their routine AVT sessions.

### *Limitations*

The study did not include caregiver characteristics in quantifying the burden of care. Significant differences in burden are observed, with reduced burden seen in higher socio-economic and financial strata. Caregivers with economic pressures face a more challenging situation, trying to balance duties of looking after a patient needing daily care, with other undertakings also requiring financial inputs. The study did not take into consideration the burden prior to the CI. In our hospital setting, we only considered postoperative patients who had already undergone three months of AVT. This bypasses a significant amount of caregiver burden associated with the surgical procedure itself.

## CONCLUSION

The present study highlights the substantial burden experienced by caregivers of children with cochlear implants, particularly in the emotional, financial, and social domains. There is no significant association of caregiver burden with gender or side implanted in the child. The distance travelled to obtain AVT poses a significant challenge which translates to overall higher burden in the carers. The use of Oh's and Pai's standardized questionnaires enabled a nuanced assessment of domain-specific stressors, revealing the multifaceted challenges faced by families in this context.

The ZBI, although originally developed for use in older adult caregiving contexts, demonstrated a moderate to strong correlation with the domain-specific measures. This suggests that ZBI can serve as a practical and efficient screening tool for identifying overall caregiver burden in clinical settings. However, its relative lack of specificity underscores the continued need for comprehensive, multidimensional assessment tools—especially in research or cases requiring detailed evaluation. These findings underscore the importance of integrating routine caregiver burden assessments into cochlear implant rehabilitation programs. Timely identification of high-burden families can inform the provision of targeted psychosocial support, counselling, and financial assistance. Additionally, there is a growing need for culturally adapted tools that accurately reflect the lived experiences of caregivers in diverse socioeconomic settings such as India. Future research should explore the longitudinal impact of caregiver burden and the effectiveness of intervention strategies aimed at reducing this burden over time.

## ACKNOWLEDGEMENTS

Authors would like to thanks the audiologists, the supporting staff of the Department of Audiology, Auditory Verbal Therapy and Speech and Language Pathology for their inputs during AVT and for patient recruitment and data collection during the study.

*Funding: No funding sources*
*Conflict of interest: None declared*
*Ethical approval: The study was approved by the Institutional Ethics Committee*

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**Cite this article as:** Chowdhary S, John M, Asif SK, Picardo N, Varghese AM. Caregiver burden in primary caregivers of pediatric cochlear implantees: a cross-sectional study from a tertiary referral centre in Southern India. Int J Otorhinolaryngol Head Neck Surg 2026;12:xxx-xx.