

Impact of paediatric cochlear implantation on family life: A conceptual framework informed by parents

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Supplementary table S1: Demographic information of paediatric cochlear implant recipients

(n=26*)

Demographic characteristic	n (%)
Age at data collection (years)**	
Mean (SD; range)	8.42 (4.54; 2 – 17)
Duration of CI experience at data collection (years) ***	
Mean (SD; range)	5.77 (4.06; 1 – 15)
Gender	
Male	12 (46.15)
Female	14 (53.85)
Communication mode	
Spoken language only	19 (73.08)
Mixed/ Total Communication	7 (26.92)
Educational sector	
Private	17 (65.38)
Public	6 (23.07)
Not applicable	3 (11.54)
Educational setting	
Not in school (too young/ < 3 years old)	1 (3.84)
Full mainstream nursery school or pre-school	6 (23.08)
Special nursery school or pre-school for children with hearing loss: oral approach (spoken language)	2 (7.69)
Mainstream school	6 (23.08)
School for children who are hard-of-hearing: oral approach (spoken language)	4 (15.38)
Special needs school: mainstream syllabus	2 (7.69)
Special needs school: special syllabus	2 (7.69)

Home school	3 (11.54)
CI device configuration	
Bimodal (hearing aid in non-implanted ear)	2 (7.69)
Unilateral CI (single-sided deafness, no hearing loss in non-implanted ear)	1 (3.85)
Bilateral CI	23 (88.46)
Additional developmental condition(s)/ needs****	
None	18 (69.23)
Cognitive disabilities	2 (7.69)
Motor disabilities	4 (15.38)
Behavioural disorders	7 (26.92)
Genetic Syndromes	
None	23 (88.46)
One or more (e.g. Waardenburg syndrome, Usher syndrome)	3 (11.54)

** For four of the paediatric CI recipients, both parents participated. Additionally, two pairs of siblings were included, of which both siblings had CIs. Of these sibling pairs, one pair had one parent who participated, and the other pair had both parents who participated. The information in this table was obtained from the demographic questionnaire completed by the parents as well as patient records.*

*** Calculated from date of birth up to the date of the last data collection session.*

**** Calculated from the date of activation of (first) CI device up to date of the last data collection session.*

***** Some CI recipients had more than one developmental disability.*

Supplementary table S2: Examples of edits made to statements

Reason for edit	Example of statement	Action
Irrelevant	<i>“He is very close with his grandmother”</i>	Removed
Too vague/ unclear	<i>“Everything has changed”</i>	Removed
Beyond the focus	<i>“Her additional disabilities make her education very difficult”</i>	Removed
More than one idea	<i>“We have to do careful financial planning as the medical aid doesn't cover all the costs of the CI device” were split into</i>	Statement was split into <i>“Medical aid did not cover all the CI costs”</i> and <i>“Financial planning and expenditure have changed as a result of cochlear implantation”</i>
Poor syntax/ grammar	<i>“Since CI, I had to change jobs because my performance dropped, and they didn't understand why I had to take so much time off”</i>	<i>“Since the CI process require commitment and time, I performed poorly at work and consequently had to change to another job (limited understanding from colleagues)”</i>
Too specific terms	<i>“As a result of increased costs, my husband isn't on medical aid anymore”</i>	Statements was edited to: <i>“As a result of increased costs, my partner isn't on medical aid anymore”</i>
Similar statements	<i>“The CI is very expensive”</i> and <i>“It had a large financial implication”</i>	Statements were combined into: <i>“Cochlear implantation is expensive and had a big financial impact on us as a family”</i>

Supplementary table S3: Clusters describing the impact of paediatric cochlear implantation on family life

Cluster (number of statements in cluster; average bridging value)	Description of cluster content	Statements (bridging scores)
Financial Outlay and Supports (16; 0,18)	The planning of financial expenditures related to the CI device and the CI process.	<p>1. Cochlear implantation is expensive and had a big financial impact on us as a family (0.003)</p> <p>2. Medical aid did not cover all the CI costs, and paying from my pocket had a financial impact on our family (0.149)</p> <p>3. In order to cover CI related costs, we had to change to a more expensive medical aid which affects us financially (0.005)</p> <p>4. As a result of the increased costs of medical aid, my partner isn't on medical aid anymore (0.032)</p> <p>5. The additional costs to insure the CI device(s) impacts us financially (0)</p> <p>6. CI device programming (mapping) has a financial impact (0.12)</p> <p>7. Placement in a specialized educational environment that is required for the CI intervention process impacts us financially (0.46)</p> <p>8. Since we live far from CI services, travelling and/or accommodation expenses impacts us financially (0)</p> <p>9. The costs for the required therapies for the CI intervention process (e.g., speech therapy, aural rehabilitation, occupational therapy) impacts us financially (0.014)</p> <p>10. The ongoing costs for the maintenance of the CI device(s) (spare parts, batteries, accessories, upgrades etc.) impacts us financially (0)</p> <p>11. Financial planning and expenditure have changed as a result of cochlear implantation (0.003)</p> <p>12. My partner/I had to stop working in order to give my child with the CI(s) the necessary support, which impacted us financially (0.072)</p> <p>13. I had to work harder to financially support my family (0.236)</p>

		<p>22. Other siblings are very aware of our family's financial limitations that resulted from CI expenses (0.956)</p> <p>53. I am worried about the CI device(s) getting lost or damaged, since there will be direct consequences (financial, inconvenience) (0.364)</p> <p>74. The positive impact of cochlear implantation was worth the financial impact (0.494)</p>
<p>Education and Therapy (19; 0,56)</p>	<p>The need to seek and access the right support required for the paediatric CI recipient and their family members, including support related to education and therapy.</p>	<p>29. I had to appoint someone to help with my child with CI(s)' home schooling and/or schoolwork (0.125)</p> <p>30. Finding an appropriate educational setting to accommodate my child with the CI(s) was difficult (0.151)</p> <p>31. The specialized educational setting requires us to get up early and travel long distances (0.252)</p> <p>32. The specialized educational setting required my child with CI(s) to board far away from home (0.252)</p> <p>33. My child was placed in mainstream education, which improved their independence, confidence, and academics (0.487)</p> <p>34. I lost time that could be used for work because of the time I spent on the therapy sessions of my child with the CI(s) (0.717)</p> <p>36. The required regular speech therapy and/or aural rehabilitation sessions are time consuming (0.703)</p> <p>40. I continuously have to explain the CI device(s) and how it works to others (0.603)</p> <p>45. It is upsetting when others (children and/or adults) make comments about or stare at my child with the CI(s) (0.6)</p> <p>46. When others (children and/or adults) make comments about or stare at my child with the CI(s), I get angry and/or frustrated (0.722)</p> <p>49. I am scared that my child with CI(s) might get bullied (0.609)</p> <p>54. We constantly have to keep an eye on the CI device(s) to prevent loss or damage (0.602)</p> <p>70. Initially I was stressed about handling the CI devices (0.487)</p> <p>81. Our home interior changed in order to improve acoustics of sound (0.782)</p>

		<p>84. Our child with CI(s)' language of instruction (language used at school) had to become our new home language (0.814)</p> <p>88. I read up on CI(s) in order to help my child and others (0.807)</p> <p>91. I don't spend time away from my child with the CI(s), since I don't know who will be able to look after them and the CI devices (0.716)</p> <p>96. The academic demands of our child with the CI(s), in terms of time and effort, has an impact on our family (0.513)</p> <p>97. We attend less functions because of the academic demands of my child with the CI (0.691)</p>
<p>Responsibilities and Sacrifices (22; 0,54)</p>	<p>Sacrifices and adaptations made by family members.</p>	<p>14. Since the CI intervention process requires commitment and time, I performed poorly at work and consequently had to change to another job (limited understanding from colleagues) (0.634)</p> <p>19. All of the CI related responsibilities rest on me (0.642)</p> <p>35. The CI intervention process requires a lot of work and dedication (0.731)</p> <p>47. As a parent I always worry about my child with the CI(s) and/or wonder whether I am making the right decisions for them (0.536)</p> <p>48. I had to change how I approach and communicate with my child with CI(s) (0.452)</p> <p>55. I am overprotective of my child with the CI(s) (0.477)</p> <p>56. I find it challenging when my child streams music through the CI(s) rather than listening to me (0.531)</p> <p>57. We have accepted that the CI(s) have become our new normal (0.512)</p> <p>64. I have learned to be accommodating and pay attention to the things that affect my child with the CI(s) (0.481)</p> <p>66. It is difficult to communicate when it is dark (at night), and the CI device(s) are not on (0.513)</p> <p>69. How I discipline and support my child with the CI(s) has changed (0.744)</p> <p>77. It is not an easy journey and there are challenges (0.529)</p> <p>79. Family events (e.g., activities, outings, holidays) requires careful planning (0.581)</p>

		<p>80. I have to make sure that my child with the CI(s) can hear all of the time, by always being prepared (e.g., spare batteries, manage charging situation when electricity goes off) (0.47)</p> <p>82. I always have to be cognisant of the sound environment (e.g., background noise, sounds) and how it will impact my child with CI(s) (0.545)</p> <p>83. I always have to be cognisant of the surroundings and how it will impact my child with CI(s)' hearing and/or CI devices (0.485)</p> <p>86. How I play with my child has changed (using language and sound during play) (0.512)</p> <p>89. CI intervention process requires a lot of my time and hence I do not have time for myself anymore (0.607)</p> <p>90. I don't want to be out of reach from the CI unit (want to be in close proximity/ have easy access when something goes wrong with CI devices) (0.52)</p> <p>92. I act as a buffer against stress for my child with the CI(s) (0.448)</p> <p>95. I have to teach and motivate my child to wear their CI device(s) (0.459)</p> <p>99. My child had to learn to take responsibility for their hearing and for the CI device (0.515)</p>
<p>Extended Family and Community (8; 0,75)</p>	<p>Support and challenges experienced due to the influence from the surrounding community and extended family members.</p>	<p>23. There is friction since the other sibling(s) feel we treat child with CI(s) differently (different rules) (0.839)</p> <p>37. We gained support from our friends and community (1)</p> <p>38. I was judged for choosing cochlear implantation for my child (0.589)</p> <p>39. My family was not supportive but sceptical about cochlear implantation and CI outcomes (0.692)</p> <p>41. Others (e.g., family members, friends) have learned to help with the handling/ management of my child's CI device(s) (0.745)</p> <p>43. My family members are hesitant to look after my child with CI(s) since they are afraid to handle/ manage the CI device(s) (0.644)</p> <p>44. There are family disagreements about how I should be handling my child's hearing health needs (0.766)</p>

		78. I still wonder whether cochlear implantation was the right decision (0.731)
Spouses and Siblings (17; 0,54)	Changes in the immediate family (such as the parents and siblings) and the family functioning in the home environment.	<p>15. My partner and I started working as a team to prioritize and accommodate our child with the CI(s) (0.488)</p> <p>16. I have new-found respect and appreciation for my partner (0.462)</p> <p>17. I now lean more on my partner than I lean on family and friends (0.54)</p> <p>18. Since we spend more time together, my relationship with my partner got stronger (0.492)</p> <p>20. My partner and I have different views regarding CI(s) and the accompanying CI intervention process (0.647)</p> <p>24. There is less time and attention available for the other sibling(s) (0.591)</p> <p>25. Sibling(s) of the child with the CI(s) feel that the CI situation is unfair towards them and/or that they are being punished (0.54)</p> <p>26. Sibling(s) of the child with the CI(s) had to adapt and learn how to communicate with and treat their sibling with the CI(s) (0.543)</p> <p>27. Sibling(s) of the child with the CI(s) had to learn to be patient and empathetic towards their sibling with the CI(s) (0.544)</p> <p>28. Sibling(s) of the child with the CI(s) take responsibility for and is/are protective of their sibling with the CI(s) (0.531)</p> <p>59. Our hope has been restored (0.425)</p> <p>61. I have more compassion for individuals and parents of individuals with disabilities (like us) (0.519)</p> <p>68. The CI intervention process made our family unit stronger (0.541)</p> <p>71. The CI intervention process requires commitment from all of us as a family (0.568)</p> <p>73. I think about the future of my child with the CI(s) (0.517)</p> <p>93. I don't want my child to see that I am worried about them and their CI(s) (0.563)</p> <p>98. After cochlear implantation, my partner/I have adopted the role of a therapist (0.563)</p>

<p>Achievements and Enrichments (17; 0,43)</p>	<p>Positive personal and functional changes within the paediatric CI recipient and their family members.</p>	<p>21. My child with the CI(s) can now communicate with their sibling(s) and/or other family members (0.426)</p> <p>42. Now that my child with the CI(s) can communicate, I am able to leave them under the care of others (0.506)</p> <p>50. The CI has enriched my life and I am more grateful (0.381)</p> <p>51. I don't take sounds and speech for granted anymore (0.343)</p> <p>52. We were brought down to earth/ were grounded as a family (0.815)</p> <p>58. I am relieved and/or happy that my child with the CI(s) can now communicate verbally (use spoken language) (0.459)</p> <p>60. I am happy and relieved that my child with the CI(s) can hear (0.371)</p> <p>62. My horizons were broadened in terms of knowledge about hearing technology (0.425)</p> <p>63. I have learned to be more patient (0.346)</p> <p>65. I am less frustrated because we (my child with the CI(s) and I) can understand each other better (0.498)</p> <p>67. I am more appreciative of my child's achievements since they received the CI(s) (0.48)</p> <p>72. I am no longer concerned about my child with CI(s)' balance and motor functioning (0.451)</p> <p>75. There was a total difference after CI (like night to day) (0.326)</p> <p>76. Our emotions has changed for the better (0.38)</p> <p>85. We are now able to go on holiday (0.508)</p> <p>87. Our lifestyle has changed since my child with the CI(s) is now more independent (I don't have to watch/ follow them all of the time) (0.326)</p> <p>94. I am at a better place and more grateful (0.332)</p>
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Supplementary table S4: Parent's perceptions of how negative or positive each possible change in family life is after paediatric cochlear implantation (Welch's t [degrees of freedom]).

Concept	Financial outlays and support	Education and Therapy	Responsibilities and Sacrifices	Extended Family and Community	Spouses and Siblings
Education and Therapy	2.9863 (33) *				
Responsibilities and Sacrifices	4.7876 (36) **	1.9943 (39)			
Extended Family and Community	1.1723 (22)	0.666 (25)	1.8844 (28)		
Spouses and Siblings	5.5261 (31) **	3.2621 (34) **	1.6053 (37)	2.8682 (23) *	
Achievements and Enrichments	12.9677 (31) **	10.1073 (34) **	7.3393 (37) **	6.3168 (23) **	3.9562 (32) **

* Significant for $p < 0.01$

** Significant for $p < 0.005$

Supplementary table S5: Parent's perceptions of how important each possible change in family life is after paediatric cochlear implantation (Welch's t [degrees of freedom]).

Concept	Financial outlays and support	Education and Therapy	Responsibilities and Sacrifices	Extended Family and Community	Spouses and Siblings
Education and Therapy	4.3002 (33) *				
Responsibilities and Sacrifices	1.924 (36)	1.738 (39)			
Extended Family and Community	5.5783 (22) *	2.6136 (25) **	3.738 (28) *		
Spouses and Siblings	1.3941 (31)	2.1863 (34) **	0.1415 (37)	4.0593 (23) *	
Achievements and Enrichments	0,7315 (31)	7.047 (34) *	2.4592 (37) **	5.9313 (23) *	1.9397 (32)

* Significant for $p < 0.001$

** Significant for $p < 0.05$