

# Health-Related Quality of Life of Pre-Adolescent Deaf Children with Cochlear Implants: A Conceptual Disease Model

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## Objective

- To develop a conceptual disease model of health-related quality of life (HRQoL) in deaf children between 8 and 12 years old using cochlear implants (CIs)

## Methods

- A targeted literature review was carried out to review research conducted in deaf children with CIs, detailing concepts relevant to their HRQoL. The literature review informed two concept elicitation studies investigating HRQoL in the patient population.
  - The work was carried out as part of a doctoral research project at City, University of London and was approved by the university psychology ethics committee (ref: PSYCH(P/F) 14/15 131).
- Interview guides focused on exploring HRQoL concepts relevant to the patient experience of being deaf with CIs.
- The first study involved qualitative interviews conducted over the telephone with seven professionals who have direct experience with the population: two clinical audiologists, two clinical psychologists, one speech therapist, one consultant surgeon and one principal teacher of the deaf.
- The second study involved face-to-face qualitative interviews with 15 deaf children with CIs between the ages of 8 and 12 years old.
- All interviews were transcribed verbatim and coded using thematic analysis<sup>1</sup> aided by NVivo version 10 software. The analysis used an inductive bottom-up approach with the data driving analysis.<sup>2</sup>
- The concepts researched in the literature review and the candidate themes identified in analysis of the two studies were used to develop conceptual disease model domains that comprise HRQoL in deaf children with CIs.

## Results

- The interviews produced domains reported by a wide range of both professionals and children (Table 1).
- The themes identified in both the literature review and the analysis of the two concept elicitation interview studies were used to develop the model (Table 2). If the themes were consistently identified as important in both the interviews and the literature, they were included in the conceptual model. If themes were seen to be less relevant they were not included in the final model.
- The final domains of the model include emotions, social relationships, school life, hearing functioning, and device limitations (Figure 1). Domains that were candidate themes but were deemed not relevant included impact of family dynamic and identity of being a CI user.
- Although issues of identity were reported as important to adolescent CI users, they were less relevant to the pre-adolescent children interviewed, and were therefore not included in the final model.
- Hearing functioning and communication were key identified as the most prominent themes, as reported by the professionals and child CI users (Figure 2).

**Table 1. Demographic Details of Deaf Children Interviewed in Study**

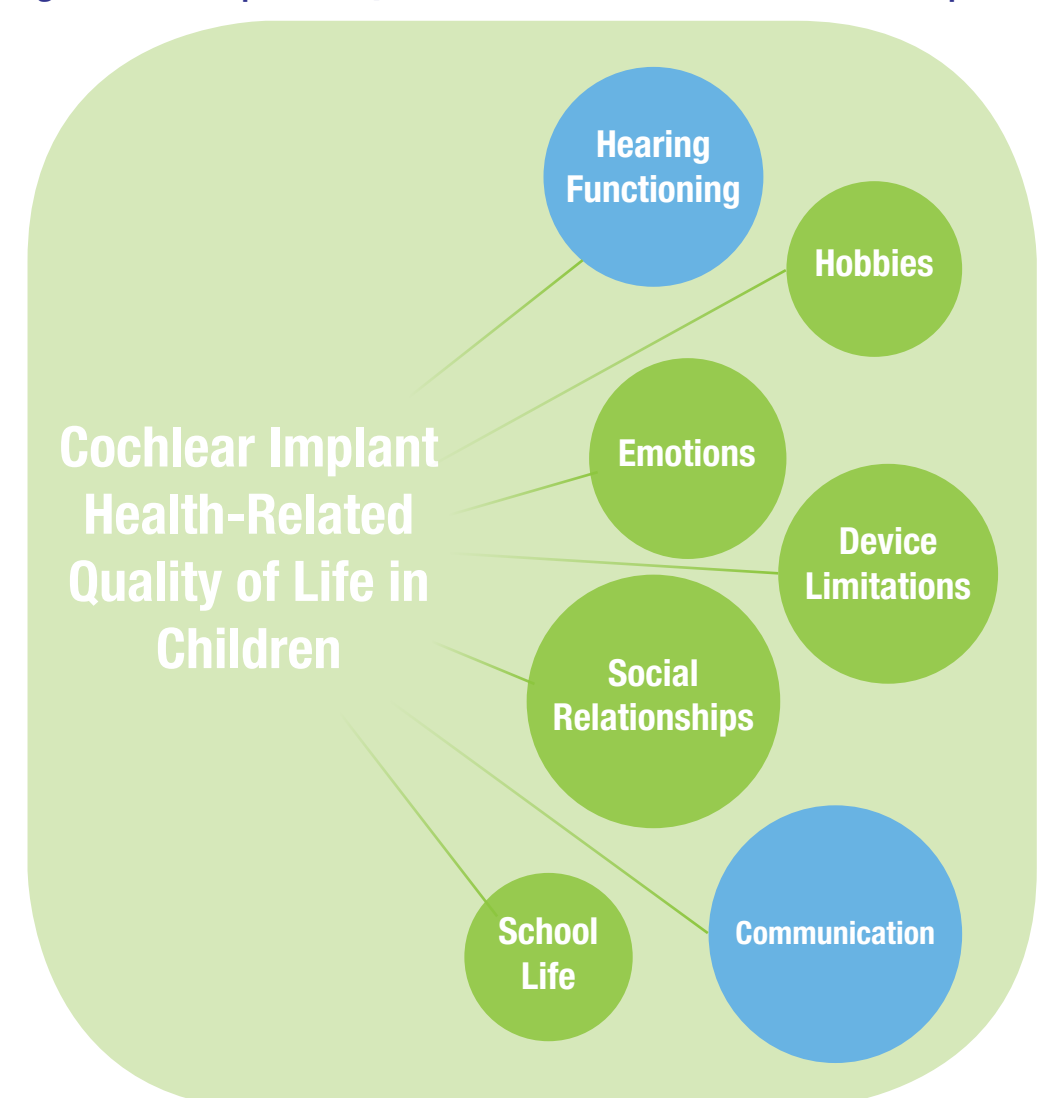
Variable	N=15
<b>Gender of Child, n (%)</b>	
Female	7 (46.7%)
Male	8 (53.3%)
<b>Age of Child at Interview, years</b>	
Mean (SD)	10.3 (1.5)
Range	8-12
<b>Illness That Caused Deafness, n (%)</b>	
Unknown	
Meningitis	4 (26.7%)
Waardenburg's syndrome	2 (13.3%)
Vohwinkel syndrome	1 (6.7%)
Connexin-26 genetic from birth	1 (6.7%)
Enlarged vestibular aqueduct	1 (6.7%)
<b>Age of Diagnosis of Deafness, n (%)</b>	
Mean (SD)	9.3 (1.5)
Range	0-40
<b>Age of First Implantation, months</b>	
Mean (SD)	23.9 (15.4)
Range	7-66
<b>Number of Implants, n (%)</b>	
Unilateral	1 (6.7%)
Bilateral	14 (93.3%)
<b>Communication Use, n (%)</b>	
Oral	11 (73.3%)
Total Communication	3 (20.0%)
BSL	1 (6.7%)
<b>School Type, n (%)</b>	
Mainstream school without deaf unit	4 (26.7%)
Mainstream school with deaf unit	8 (53.3%)
Specialist deaf school	3 (20.0%)

Abbreviations: SD = standard deviation; BSL = British Sign Language


**Table 2. Development of HRQoL Conceptual Model**

Study One – Professional Candidate Themes	Study Two – Children Candidate Themes	Conceptual Model Domains
Emotional Well-Being	⇒ No associated theme in this study	Emotions
Identity of Cochlear Implant User	⇒ Relationships	⇒ Social Relationships
Communication	⇒ Communication	⇒ Communication
Impact of Family Dynamic	⇒ Relationships	⇒ Social Relationships
School Life	⇒ School Life	⇒ School Life
No associated theme in this study	Ability to Hear	⇒ Hearing Functioning
No associated theme in this study	Hobbies	⇒ Hobbies
No associated theme in this study	Logistics and Technical Issues	⇒ Device Limitations

**Figure 1. Conceptual HRQoL Model of a Deaf Child with Cochlear Implants**




**Figure 2. Child CI User Quotations of Hearing Functioning and Communication**



**Hearing Functioning**

If I turn them off and, or take them off, um, I can't hear anything, so massive improvement with them on. (Alfie, 8 year old boy)

Can hear most things. It's only really when people are talking really loudly over them that I can't really hear anything (Huda, 12 year old girl)



**Communication**

Loads of people say I speak very well for a deaf child. *And uh, how does that make you feel?* Uh, happy. (Ciaran, 8 year old boy)

My eyes are used more than my ears because if, so like if we talk something, someone's whispering to me I can't exactly hear what they're saying. Um, so I usually have to look at the person's lips. (Ada, 12 year old girl)

## Conclusions

- A wide range of topics have an impact on the HRQoL of a child CI user, but themes of communication and hearing functioning were reported as being the most important.
- At present, there is no condition-specific patient-reported outcome measure for deaf children with CIs.
- The conceptual HRQoL model presented has the potential to be used for development of such a measure assessing HRQoL in deaf children with CIs.

## References

- Braun V & Clarke V. Using thematic analysis in psychology. *Qual Res Psych*. 2006;3(2):77-101.
- Patton MQ. *Qualitative Research & Evaluation Methods: Integrating Theory and Practice* (Fourth ed.). Los Angeles: SAGE; 2015.

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