

Ototoxic Hearing Loss among Childhood Cancer Survivors:
Parent, Audiologist, and Teacher Perceptions of Facilitators and Barriers to
Successful Hearing Rehabilitation

Executive Summary

The treatment of childhood cancer is one of the great medical success stories of the last few decades. In the United States alone, more than 12,000 new diagnoses of childhood cancer are reported annually, with a 5-year survival rate of almost 80%. However, as drug therapies have become more powerful, so, too have their side effects. One especially strong and effective group of chemotherapeutic agents used to combat malignant solid-mass tumors – platinum-based drugs -- also cause permanent bilateral high frequency hearing loss in many young cancer survivors. Many of these children will need hearing aids and special support to help their language and speech skills develop. Their parents will need support too, as they play a vital role in providing a home and communication environment that encourages listening, speech, and language skills, in the context of very vulnerable circumstances. However, parents of children who have survived cancer but acquired hearing loss face unique challenges, and researchers know very little about these challenges or how best to support parents to participate in their child's hearing rehabilitation.

A multidisciplinary research team composed of a Special Educator (Deaf Education), an Audiologist, and a Counselling Psychologist (Janet Jamieson, Beth Brooks, and Marla Buchanan, respectively) sought to address this gap by exploring a) how parents of children diagnosed with *both* cancer and hearing loss from cancer treatment experience the dual diagnosis, and b) the challenges to successful rehabilitation confronted by children and parents, from the perspective of audiologists and teachers of the deaf and hard of hearing.

Method

The study was divided into two parts, both conducted in the province of British Columbia, Canada: parent interviews and surveys with public health audiologists and teachers of the deaf and hard of hearing.

Parents whose children were between 2 and 18 years of age, had completed cancer treatment at least one year previously, and had acquired hearing loss through their cancer treatment were recruited for the interviews. Two parents have been interviewed to date, with three others scheduled. The parents were interviewed by the PI (one in person, one by phone), and the interviews were transcribed, and analyzed using a thematic content analysis (Braun & Clarke, 2006). Data were managed with NVivo12 software.

Online surveys were developed, and audiologists and teachers who had worked with children who had acquired hearing loss through cancer treatment were invited to respond. Each professional could present up to four anonymous cases of

children; 8 audiologists presented 26 child cases and 18 teachers presented 42 child cases. Descriptive statistics were used to analyze the quantitative findings, and thematic content analysis was used with the narrative responses.

Key Findings

Parent interviews -- Predominant themes:

- The main concern was survival; hearing loss was secondary, and often challenging to understand and surprising to parents in terms of its impact on the child's and family's daily life.
- The needs of developing an understanding of and accommodating for hearing accessibility, following the emotionally exhausting year of cancer treatment, resulted in a "new norm" in families.
- Both Teachers and Audiologists perceived the nature of the hearing loss (high frequency, sometimes not affecting speech intelligibility) to be a major barrier to successful adjustment, in that others often underestimated its impact.
- Parents strongly recommended counselling for emotional support throughout and following treatment, in recognition of their unique journey, challenges, and "new normal."

Teacher and Audiologist surveys – Predominant themes:

- Teachers perceived the children's greatest needs to be social-emotional issues and academic challenges arising from or complicated by the acquired hearing loss.
- Audiologists perceived the children's greatest needs to be support of all kinds – academic, social-emotional, and in terms of managing equipment.
- Both Teachers and Audiologists perceived the nature of the hearing loss (high frequency, sometimes not affecting speech intelligibility) to be a major barrier to successful adjustment.
- Both Teachers and Audiologists perceived the families' greatest needs to be support of all kinds, but primarily social-emotional to facilitate family adjustment.

Conclusion

Parents whose children acquire hearing loss through cancer treatment confront many of the same challenges as parents of children with hearing loss, but appear to experience the dual reality of cancer *and* hearing loss differently. In particular, the parents, the teachers, and the audiologists all describe intense emotional demands on both parents and children, as well as a frequent misunderstanding by parents of the far-reaching impact of hearing loss on their child's wellbeing.

More specifically:

Parents

- *understand* hearing loss initially as of secondary importance; begin to understand its impact only after treatment
- *experience* hearing loss as intertwined with cancer

Families

- find a “new normal” – with child, sibling, parent, and family adjustment needs
- have a strong, pervasive need for social-emotional support

Audiologists and Teachers of the Deaf & Hard of Hearing

- are well positioned to provide limited but important support through *collaboration* and *consistency*
- need both person-centered and family-centered awareness and skills
- often report emotional challenges in supporting children who have survived cancer and their families