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The Experience of Hearing Loss in Adult Survivors of Childhood and Young Adult Cancer: A Qualitative Study

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Abstract

Background: Hearing loss is a prevalent late effect amongst cancer survivors. Despite the significant social costs, there is a noted delay in seeking care and there are limited data on the lived experiences of cancer survivors with hearing loss. The aim of this study is to explore the lived experience of hearing loss in survivors of childhood and young adult cancers in order to guide survivorship care.

Method: Twenty-four survivors participated in semi-structured telephone interviews. Inclusion criteria consist of a clinical visit at the Adult Long Term Follow Up Program at Memorial Sloan Kettering between September 2005 and January 2019, exposure to cranial radiotherapy, platinum chemotherapy or both, and hearing loss as evidenced by clinical notes, use of hearing aids, or audiogram levels consistent with severe ototoxicity.

Results: Three primary themes emerged from the interviews. First, post-treatment hearing loss is associated with isolation and feelings of exclusion. Second, clinicians play an important role in providing survivors with education about hearing loss and hearing aids. Finally, hearing loss for

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survivors may be de-prioritized as it is a reminder of the cancer history and interpreted in the context of other treatment-related late effects.

Conclusion: Clinicians play an important role in initiating the discussion on hearing loss with survivors given the importance for hearing to maintain social relationships, the availability of hearing care interventions, and the invisibility of hearing loss. Education about the value of treatment may have implications for how survivors choose to prioritize hearing loss and seek care.

Keywords

ototoxicity; survivorship; hearing; pediatric cancer; qualitative

Introduction

Hearing loss is one of the most common adverse effects of cancer treatment¹⁻³. Several studies have shown that hearing loss is a prevalent late effect of cisplatin or carboplatin chemotherapy and radiotherapy to the cochlea. A recent study of 23,000 survivors of childhood cancer survivors diagnosed between 1970 and 1999 showed increased incidence of hearing loss over time even as the incidence of several other late effects decreased⁴. Prior studies suggest that many childhood and young adult cancer survivors have severe hearing loss that could benefit from hearing aids and that, for some, hearing loss worsened years after treatment^{5,6}.

Unfortunately, the social consequences of hearing loss can be profound. In older adults, hearing loss has been associated with depression, cognitive impairment, and social isolation⁷⁻⁹. Among children, even mild levels of hearing loss have been associated with language and learning problems, increased stress and lower self esteem^{10,11}. Hearing loss in childhood cancer survivors has been associated with higher unemployment rates and reduced likelihood of marriage or living independently, even after controlling for other disability-related factors¹².

At the same time, there is little qualitative data on the experience of hearing loss in childhood and young adult cancer survivors. Existing qualitative studies on hearing loss have been conducted in children and older adults with unilateral, congenital or age-related hearing loss. Furthermore, most of these studies have used multiple-choice questionnaires and validated scales to assess functional status and quality of life measures.¹³⁻¹⁶ It is important to note two qualities of the childhood cancer survivor population that makes it uniquely suited for this investigation: (1) these survivors are young, and face cancer treatment-related hearing loss over the lifespan, and (2) they are at risk for multiple treatment-related toxicities which may impact the experience of hearing loss and hearing therapy.

Despite significant consequences of untreated hearing loss, there is often a delay between recognition of hearing loss and help-seeking behavior. Past studies suggest that individuals can wait up to ten years from the time they become aware of their hearing loss before accessing hearing care services^{7,17}. In a qualitative study of hearing impairment amongst students in South Africa, students chose not to disclose hearing loss out of a desire to be

seen as normal in a culture of hearing individuals. As a result, they relied upon personal coping strategies rather than institutional support¹⁸.

Qualitative data is uniquely useful for understanding the “how” and “why” of complex phenomena, which can improve hearing care in survivorship and survivors’ experiences living with this late effect¹⁹. In this paper, we aim to describe to the lived experience of hearing loss after treatment in order to inform policy, care, and future interventions for survivors living with hearing loss as a late effect. The definition of “cancer survivor” is complex and is embedded in discourse about the heterogeneity of the cancer experience and the role of advocacy²⁰. Since this study addresses the experience of hearing loss after cancer treatment is over, the participants in this study have all completed therapy.

Methods

Participants were drawn from the Adult Long-Term Follow-Up Program (ALTFU) at Memorial Sloan Kettering (MSK). This service was established in 2005 to provide longitudinal risk-based care to adult survivors of childhood and young adult cancer. Patients need to have been treated for cancer or a related illness before the age of 40 years. Most patients were treated on MSK Kids; the most common diagnoses are leukemia, lymphoma, brain tumors, sarcoma, and hematopoietic cell transplant. Patients with a history of treatment that can cause hearing loss or who have signs or symptoms of hearing loss are referred for audiological testing.

Eligibility criteria for this study included at least one clinical visit at the MSK ALTFU Program between September 2005 and January 2019, exposure to cranial radiotherapy, platinum chemotherapy or both, and hearing loss evidenced by documentation in a clinic note, use of hearing aids, or audiogram hearing levels consistent with severe ototoxicity according to two ototoxicity scales, either the Chang or International Society for Paediatric Oncology (SIOP) grading criteria²¹. Patients who were non-English-speaking and those with severe neurocognitive impairment were excluded as these factors precluded participation in the interview.

Eligible survivors were contacted by a message sent through a secure online patient portal. Non-respondents were contacted by phone within one week of the portal message. Survivors who expressed interest were then contacted by phone to schedule an interview. Of 99 eligible patients identified, 59 were active on an online patient portal and received a message about the study. Of the 59 patients contacted, 24 agreed to participate in the study. Among non-participants, 7 patients declined, 3 had severe neurocognitive impairment, one did not speak English, and 24 did not respond to the portal message or follow-up phone call.

Participants were sent a written letter describing the study and were verbally consented. A telephone interview was chosen for data collection because it allowed for the greatest inclusion of participants. Participants’ schedules were accommodated so that they could communicate in a setting and with devices that allowed them the greatest ease of communication.

One author (AK) interviewed the 24 patients by telephone call. Interviews were conducted and recorded using WebEx software (Cisco WebEx, Santa Clara, CA, USA). A semi-structured interview guide was designed to understand survivors' experience of living with hearing loss, using hearing aids, and interacting with clinicians and audiologists. Where appropriate, further questions were asked for clarification based on the experiences participants chose to share. Interviews were transcribed verbatim from these recordings. In a stepwise manner and using an inductive approach, thematic analysis was used to identify themes as well as similarities and differences between participant experiences^{22,23}. One investigator (AK) read and coded all 24 interviews as a first pass. In the second pass, a second investigator (ET) read and coded all 24 interviews. Subsequently, three authors (AK, ET, and SW) grouped these codes into categories according to their similarities, organized these categories into themes, and identified quotations that corresponded to the themes. In the final step, all authors evaluated these findings and agreed upon the most salient themes to be highlighted for the manuscript.²³ This study was approved by the Investigational Review Board at MSK. No personal health information was collected.

Results

Three primary themes emerged from the interviews. First, hearing loss related to cancer treatment may be associated with isolation and exclusion in social, professional and academic settings for the adult survivor of childhood cancer. Second, survivors display a knowledge gap regarding hearing loss and possible interventions like hearing aids. Finally, hearing loss for survivors is often de-prioritized or neglected as it is a reminder of the cancer history and interpreted in the context of other treatment-related late effects.

"Feeling Left Out"

Social exclusion is a common experience for survivors due to feeling left out of group experiences, difficulty communicating in social settings and challenges with disclosure of hearing loss. One survivor recalls her experience of exclusion from a class-wide trip after her cancer treatment:

"In 8th grade, my school went on a graduation trip. Everybody was excited. I was excited. We were going to go to Canada. A couple of days before we were about to leave, the teacher pulled me out of the classroom and told me it was decided that they didn't want me to go because I had trouble hearing. So that kind of hit hard because everyone else went to Canada and I didn't, and that kind of still sticks with me today."

Not only can survivors feel deliberately excluded from experiences, but the exclusion can also be subtler. Highly interactive environments can provide challenges for survivors with hearing loss in terms of understanding the conversations and asking for help. One survivor noted the challenges of socializing in groups in the presence of background noise:

"Especially like the bar scene, like that was definitely a place where I had a lot of trouble hearing. Everything was all garbled and it was just difficult for me to talk to other people in those situations."

Another survivor describes how hearing loss can produce barriers to participation in group conversations:

“Instead of asking what and people to repeat themselves numerous times, and it’s not going to be super important, I kind of like nod along. If there’s a conversation happening that I don’t feel is super important, if it’s just people joking around, I just don’t really participate”.

Another survivor also speaks to the exclusion from conversations, a theme very prevalent in the interviews:

“I think in the past couple of years, I’ve definitely been less inclined to be in close conversations about important topics, because I’m afraid that I’ll miss something in conversation. I think that might be a common occurrence, where people might be saying something to me and I don’t react because I don’t hear them. And they don’t gesture towards me or anything to get my attention so it’s hard for me to catch when there are cues”

Not only can survivors feel excluded in social settings, but the challenges of hearing loss in these settings can also lead to anxiety. One participant reported:

“I do have bad social anxiety, I hate speaking in front of people. It makes me wonder, sometimes I think, maybe I don’t want to speak up because I’m not sure what someone said.”

This anxiety may also lead to social exclusion with some survivors noting they avoided situations associated with anxiety. For example, one survivor reported:

“It had become awkward for me when I went out in certain situations...It might be something that lends into social anxiety in certain situations. Because I know that I’m probably going to have to get uncomfortably close to someone’s face to hear them talk if we’re in a crowded room. So, for me, it would be sometimes avoiding situations like that.”

Finally, hearing loss can lead to social fatigue. One participant said:

“Being in social work, like social situations where I’m doing a lot of interacting especially with new people is exhausting for me. I have to base it off tone and word choice and tempo.”

With all of the associated challenges related to anxiety, fatigue and concerns about missing important information, it is not surprising that survivors might prefer to avoid such situations.

Social exclusion is not an infrequent experience amongst survivors with hearing loss, and these experiences of exclusion can lead to feelings of social isolation, defined as the distancing of an individual from his or her network of relationships²⁴. This feeling of isolation may be related not only to exclusionary experiences, but also to the challenges of disclosing the hearing loss. For survivors, sharing their hearing loss is uniquely challenging because of its inextricable link to the cancer history. One survivor reports,

“I’m almost hesitant to share any of it because there’s so much I have to share to give the background information, you know what I mean? So if I were to say, ‘I’m hearing impaired’, ‘have you always been hearing impaired’, ‘no, I got it from cancer treatment, I had cancer twice and the whole thing’. Every time I have to explain it to people I’m hearing impaired, it’s going through the whole spiel over and over again so it’s kind of a burden.”

As illustrated, disclosing hearing loss poses the risk of social isolation. At the same time, the challenges of communication can make it difficult to meet new people. . One survivor speaks to this experience of the unique social challenges associated with meeting new people and expanding the social network,

“I notice that with a group of people, or if I am with people I don’t necessarily know, if I can’t hear what they are saying, sometimes I’ll just act or pretend like I understand what they’re saying instead of saying ‘what did you say?’ After the third time I just kind of give up, but my friends will tell me because they understand. But if it’s people I don’t really know that well, I just don’t really get into explaining the long story so sometimes I’ll just act like I heard what they’re saying even though at times, I don’t.”

As this survivor notes, experiences such as these which are subtle in exclusion can lead to survivors feeling more isolated within their social networks.

The risk of social isolation is further increased by the ways in which hearing loss has been described as an invisible condition²⁵. This produces challenges for recognizing the ways in which hearing loss impacts social relationships. For some survivors, the invisibility of the hearing loss may be compounded by the invisibility of survivorship. One survivor says,

“I don’t present as someone who had cancer twice and experiences a lot of late effects. I look normal, but I have a lot going on that you can’t see. And sometimes that’s an uncomfortable thing for people to deal with. Especially when I seem fine and functioning normally.”

This survivor has powerfully noted the discrepancy between how she perceives herself and how others perceive her, as well as the implications for what might occur if the discrepancy were resolved. She notes that it would “be an uncomfortable thing”. The invisibility of her experiences is also a risk for increased social isolation as there is a limited opportunity to understand and address the needs that her hearing loss may require.

“I would have liked to know”

Diagnosis is a powerful tool by which patients can understand their experience and also communicate their experience to others. However, the absence of a hearing loss diagnosis and a diagnosis without patient education can cause confusion. Audiologists play an important role in providing education and contributing to survivors’ understanding of their hearing loss. Survivors who experience hearing loss and follow up with an audiologist report that this relationship has improved their understanding of hearing loss.

One survivor with hearing loss and tinnitus who did not know at the time of her treatment that hearing loss may be a late effect says, *“I guess I would have liked to know that this was a possibility at treatment. But I didn’t know hearing loss would be an issue. [The audiologist] definitely made it clearer as to what the initial problem was. Because between previous audiology tests, they never were really able to give me a clear cut of why I had a ringing in my ears. So then this audiologist actually defined the problem for me.”*

This survivor further clarifies the very important role of the audiologist and notes that the challenges of hearing loss were so great that it led to, as she describes, *“a breakdown in my doctor’s office...the hearing was a big part because people were making fun of it and I’m trying to laugh it off as well, but it was a big issue. So I wasn’t able to laugh it off as they were because I really can’t hear, or it’s embarrassing talking in front of people because I may say one thing and you’ll hear another thing. Or you’ll say one thing to me and I’ll hear something completely different.”* She further says, *“It’s hard to explain something that you have no knowledge or any reason of why it happened. And I really didn’t have a full answer as to why I had a ringing in my ears until I actually went to see an audiologist.”*

Another survivor describes the role of her audiologist in recommending hearing aids as a preventative measure. She shares a clinical encounter in which the audiologist *“handed me a clinical trial about, if you do not hear certain frequencies or certain sounds for x amount of years, how, later on, your brain might not be able to acknowledge them. I think that was the big thing. I was like, if it gets bad, then I’ll get hearing aids. And the audiologist said, ‘listen you could ignore this for thirty years, and then, when you’re fifty, if you want to get hearing aids, your brain might not recognize these sounds anymore since it’s been so long since they’ve been able to hear them.’ And I think that’s kind of what really opened my mind. As much as I’m so happy that I’m past treatment, I can’t ignore the things that happened.”*

This survivor’s perspective on the value of hearing aids changed after her audiologist provided her information on the preventative value of hearing aids and the association between hearing and cognition. The clinical interaction with the audiologist is a great source of education about the cause and nature of hearing loss, long-term prognosis, and options for intervention.

“We made it through”

Hearing loss uniquely impacts adult survivors of childhood and young adult cancer. Many survivors express gratitude for having survived the cancer and a desire to move past the experience, which makes acknowledgement and treatment of hearing loss particularly challenging. In addition, survivors with hearing loss may compare themselves more often to other survivors with late effects rather than other hearing impaired individuals. One survivor says,

“I’m happy that I have what I have. I think a lot of that comes from survivorship, right? We made it through, I’m great, I’m healthy, there’s so many people that aren’t that it’s just like one of the scars you bear, and you just suck it up. You kind of learn to live with some side effects.”

The burden of contending with late effects after the intense experience of cancer diagnosis and treatment can be overwhelming. As one survivor says,

“I really truly felt like admitting to and getting assistance for hearing loss is almost like acknowledging that my cancer treatment is still with me. “

Not only may survivors accept late effects as an acceptable cost of survival, the impact of late effects may be minimized when survivors compare their circumstances to that of other survivors. One survivor compares himself to other survivors:

“When you’re around other people who obviously have way worse problems, you know physically and mentally, than I do, obviously you’ve got to feel sad for them, but you’ve got to also feel that I was really lucky”.

The feeling of gratitude for survival and comparison of themselves to survivors with greater challenges can further contribute to hearing loss being perceived as an acceptable cost of survival.

Finally, hearing loss for cancer survivors is often compounded by additional concurrent late toxicities. The result is that hearing loss may cause greater challenges due to the interaction with other late effects. One survivor who has experienced attention deficits and hearing loss after treatment reports how hearing loss and the cognitive late effects interplay:

“Taking in information and processing takes longer and is more burdensome than it would be if I wasn’t hearing impaired, and with attention on top of that. It’s harder to synthesize information when it takes longer to come in. It takes a lot more energy to pay attention to specific information points. “

The impact of multiple late effects after treatment also moderates how survivors perceive the severity of the hearing loss. One survivor who had contemplated hearing aids yet was also facing post radiation changes to her teeth says:

“I’m going through some changes with my teeth and I’m not super confident about the way that I look right now either. So I just don’t think I need more attention to the way that I look now. It’s just been a lot to like deal with. I think when I start feeling more confident about how I look, like with my teeth, I won’t care as much about hearing aids.”

For survivors living with the burden of several late effects, hearing loss may be perceived as lesser priority than other late effects. This may be due to many reasons. One is the difficulty of realizing the extent of hearing loss. One survivor recollects how her peers helped her recognize her hearing loss:

“I would try to keep up with conversations and try to fill in the blanks. But it was just very evident that I struggled in those situations. Oftentimes, it would be people pointing things out, saying ‘do you hear that’, and I’d be like, ‘I have no idea what you’re talking about’. It was almost like I didn’t know I was missing things, so it wasn’t that big of a deal.”

In addition, many survivors have found ways to adapt, including lip reading, carefully positioning oneself in social settings, and communicating via text messaging more

commonly. Of his hearing loss, one survivor says, “*for a good chunk of things, you can find ways around it*”.

However, for those survivors with access to hearing care, the resulting improvement can significantly ameliorate the impact of the hearing loss and has the potential to make it one of the less burdensome late effects. One survivor describes her experience of receiving hearing aids:

“I remember the first day I got them, it opened up the whole world to me. I remember walking out with my mom that day and being able to hear even the wind blowing and birds singing and sounds I just haven’t heard for years and years”.

This survivor also shares what might have been different had she received hearing aids sooner:

“I would have excelled more at school. Even though I was doing well, I think I would have done so much better. But even socially, being able to hear my friends and hear what they are talking about and even hearing what’s going on in the room because a lot of times I felt just so left out. Even if they weren’t leaving me out, I felt left out, like I didn’t fit in.”

Another survivor who had several late effects from treatment and who wears hearing aids said:

“It’s probably the least of the long-term effects from my treatment. It’s annoying, but I have great hearing aids. I’d have a very hard time communicating with my family, doing my work. I think I’d be completely useless. We’re having some friends over tomorrow night, and I couldn’t do that if I didn’t have the hearing aids.”

Overall, it is clear that acquired hearing loss in cancer survivors is different from other kinds of hearing loss. The perceived severity of the hearing loss is moderated by its relationship to other late effects, by survivors’ comparison of themselves to other survivors, and by the ways in which survivors have processed their own experiences with diagnosis and treatment.

Discussion

Survivorship after childhood and young adult cancer is an ongoing process in which there is a meaningful opportunity for clinicians, nurses, and audiologists to provide care and counseling for those with hearing loss. Understanding the experience of hearing loss and the implications for social interaction is crucial for treating and designing interventions for this population. Previous quantitative and qualitative studies of hearing loss have found associations between hearing loss and functional status and quality of life measures^{8,12}. Social isolation is associated with hearing loss in adults⁷⁻⁹, while stress and poor self-esteem have been described among children with hearing loss^{10,11}. Our study adds to this understanding by providing novel insights gained through detailed qualitative interviews conducted in 24 survivors of childhood and young adult cancers and powerfully demonstrates the critical impact of acquired hearing loss in social connectedness as well as the benefits of providing education to cancer survivors on the risk and outcomes of acquired

hearing loss. Based on what we learned from participants in this study, we have several recommendations to improve care for the hearing-impaired childhood or young adult cancer survivor.

First, the risk of social isolation and associated concerns of social fatigue and anxiety is important to address, particularly in light of the increasing prevalence of loneliness and isolation²⁶. In addition, this late effect impacts individuals at an important phase in social development as they enter young adulthood and are typically increasingly mobile or forming new social networks. Clinicians can inform survivors that they are not alone in this experience; many other survivors are similarly affected. A study of students with hearing impairment concluded that there is a role for self-advocacy and teaching students with hearing impairment how to negotiate for accommodations¹⁸. Finally, clinicians can provide an opportunity to discuss disclosure, to advocate, and to advise regarding the best methods for self-advocacy.

Hearing loss has been described as both an invisible condition and a concealable stigma²⁷. For survivors with considerable hearing loss, the effort of concealment can result in lower self-efficacy, lower self-esteem, and minimalizing of the impact of hearing loss²⁸. Invisible conditions such as hearing loss require increased awareness because of the greater risk of them going unrecognized and consequently, undertreated. As survivors in this study note, lack of recognition of their cancer treatment as the cause of their hearing loss led to a delay in seeking care. Therefore, there is an opportunity for clinicians to proactively initiate this discussion and contribute to raising awareness of cancer treatment-related hearing loss and its impact on survivorship.

There are several limitations of our study. Participants had utilized survivorship care, which may not be reflective of all survivors with post-treatment hearing loss. Additionally, selection bias may be present. Survivors who were contacted may have already been more engaged in survivorship care. Survivors electing to participate in this study may have been more deeply impacted by late effects. However, efforts were made to reach out to survivors with varied treatment exposures, ages, and cancer history. Finally, this population of survivors in particular may have had challenges with a phone interview given their hearing loss, and the sensitivity of this information and willingness to share may be moderated by survivors' personal experience and rapport with the interviewer who was not previously known to the participants. A prior study explored the relative strengths and weaknesses of phone interviews as a method of qualitative data collection²⁹. Despite concern that a lesser rapport is established with phone as compared to in-person interviews, the authors demonstrated that this effect can be reduced by pre-interview communication conveying the purpose of the interview and by the interviewer making a concerted effort to be relational and responsive. In addition, phone interviews provide the benefit of reaching a geographically and functionally widespread and otherwise difficult to reach population, and some individuals may have greater comfort speaking over the phone as a result of increased anonymity²⁹. Finally, the interviews were conducted at a particular moment in time and limited to a discussion of particular questions from the interviewer and experiences shared by the participant that may not be representative of the totality of survivor experiences.

As one survivor in this study noted, survivorship is an ongoing and active stage. Cancer survivors are developing identities in new academic, social and professional spheres while also navigating the impact of several late effects and critically evaluating the risks and benefits of seeking support. In the case of hearing loss, clinicians should expect to initiate a discussion on the experience, given the importance for hearing to maintain social relationships and networks, the availability of hearing care options and interventions, and the invisibility of hearing loss.

When asked what advice she would share with other survivors, one survivor says, *“The best thing is to be vocal about it and advocate for yourself.”* The medical community has an opportunity to support survivors in this advocacy by raising awareness as well as initiating and continuing the discussion of the impact of late effects of cancer treatment.

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