

Tinnitus: A Deafhearing Phenomenon

Qualitative Inquiry
2015, Vol. 21(2) 173–174
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DOI: 10.1177/1077800414542700
qix.sagepub.com



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Abstract

The authors of this article are cousins from a Deafhearing family. Andrew is profoundly Deaf while Sara is Hearing. Both authors have Waardenburg Syndrome and are experiencing tinnitus, which appears to change in nature over time. This article, which is a reflection on their shared experiences of tinnitus, began as a conversation via Facebook. Through performance autoethnography, presented as poetry, they examine the Deafhearing phenomenon of tinnitus. They explore its impact on their everyday lives and together attempt to understand their stories through reflecting, writing, and performing as inquiry.

Keywords

Waardenburg syndrome, Deaf, Hearing, genetics, autoethnography, identity, Deafhearing, family, tinnitus, poetry

The Original Post and Subsequent Conversation

(Sara)

I'm experiencing more
and more
ringing in my ears . . .
It's very distracting . . .

(Andrew)

Lifetime of that for me
you get used to it.
Your brain gets retrained
to ignore it.

(Sara)

Funny you should say that cuz
because I think that's what's happened
in reverse.
When I was little I had ringing
and we went to a specialist.
But he told me it was only
when I had a cold and things
and I agreed, because
he seemed to know more about it than me!
I've noticed it over the years
But I tried to ignore it, scared of what it means;
strangely ashamed.
But recently, when making the documentary for S4C¹
I talked about it, and thought about it, and now I hear it
more and more—and it's loud!

Not just ringing—fizzing, popping, then a high pitch sound
changing, higher, then jumps higher still;
like someone is cranking up a lever.
Hard to tell if the sound is really there,
or just in my ears.
One night, so loud, and seemed so near,
I couldn't sleep!

(Andrew)

Yeah, it's only noticeable when
you are sitting down relaxing
or watching TV.
Once in a while my vision goes funny
like the room spins round in one quick bang
and my balance goes and then there's a
loud wheeeeeee in my ears.
My balance is bad in general.

(Sara)

Yeah it changes doesn't it.
There's currently a very light wheeee
in my right ear—constantly for the last few minutes.
Oh! Your balance is bad too?
Why have we never discussed this before?!

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Sometimes I actually fall over and walk into sides of doors and things.

Coping Mechanisms

(Andrew)

Have you got an MP3 player?
Get some soft, soothing music and listen to it.
Apparently it works to offset the tinnitus . . .
but it won't work in my case heh heh!

(Sara)

Well that makes sense because
I notice it more when there's silence
I'll try some soothing music, thanks!

More Than Just Ringing

(Sara)

I've noticed a strange, different version
Cuz do you ever get tinnitus where
It feels like shock waves?
Like someone has hit a gong or there has been an explosion
and the reverberations, from the blast
are quite quiet themselves but
seem to eclipse or dampen
all other sounds around you?

(Andrew)

Yeah loads of times!
Sometimes it's like a bomb—boom!
Then my eyes swirl round
as if I have spun round the room
but I haven't and it has happened
in a split second.
Then a long wheeee whistle, winding down.
then to a ringing ring, noise.
I prefer the boom type because
it slows down the tinnitus
rather than the ringing one which
goes on forever.

A Deafhearing Phenomenon

(Sara)

I had never thought, before you said,
that Deaf people can have tinnitus too
but of course they can because,
the sound is inside their heads, not outside.

(Andrew)

Yeah lots of Deaf people
Experience tinnitus.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Note

1. Welsh language TV channel.

Suggested Reading

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Author Biographies

Sara Louise Wheeler is a research assistant at the Health and Community Care Research Unit (HaCCRU), University of Liverpool. She is currently working on a project about "Habilitation" (mobility and independent living skills) training for children and young people with vision impairment. She is also a visiting research fellow at the Institute of Health, Medical Sciences and Society, Glyndŵr University, Wrexham. While Sara is "*h/Hearing*," her interest in Deaf studies research stems from the hereditary deafness in her family due to Waardenburg syndrome. She is also from the Welsh-speaking community in North Wales and her current research interests include exploring the navigation of multiple-minority space and plural identity by Deaf individuals who are from minority communities within their family contexts. Her future plans include obtaining funding to conduct an ethnographic study of Deaf Welsh identity, including the perspectives of Deafhearing, Welsh-speaking families such as her own.

Andrew Glyn Hopwood works as a financial clerk in Mark & Spencer Bank in the Integrated Support Services department, dealing with all chargecard, loans, savings, credit card, and current bank account correspondence. He has been Deaf since early childhood, is a native user of British Sign Language, and is an active member of the Deaf community, including having previously held the post of director in the British Deaf Association in London, and various posts including secretary, treasurer, and chairman for Deaf Access Wales based in Wrexham. He is heavily involved with County darts, and in his spare time, flies radio-controlled model planes. He also has a keen interest in his family's Welsh heritage and is currently learning the Welsh language to facilitate his research interests.