First Opinion Podcast
Episode 28: An ENT physician & patient on the high cost of hearing loss
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Frank Lin
Reading an excerpt from his First Opinion essay:
When Anne Madison noticed her hearing was declining at age 66, she struggled. She had always prided herself on being a savvy health care consumer. But when it came to hearing loss, what were her options? Ads for hearing aids seemed predatory, visits to an audiologist for objective professional advice about how to address hearing loss weren't covered by Medicare. And since Medicare also didn't cover hearing aids, the price tag was far out of her reach. Anne's story is a common one. Hearing loss affects over 40 million Americans, and it's understood to be the leading risk factor contributing to the development of dementia. Because a pair of hearing aids are prohibitively expensive, less than 20% of people who would benefit from hearing aids actually have them. Millions of Americans could potentially improve their health and lead better lives if hearing aids and related hearing care services were more affordable and easily accessible.

Pat Skerrett
That was ear, nose and throat physician Frank Lin, reading from the First Opinion essay he wrote with fellow physicians Charlotte Yeh and Christine Cassel titled, "Making hearing aids affordable isn't enough. Older adults also need hearing care services." We're also joined by Anne Madison, who struggled getting hearing aids and services Frank describes in the essay. I'll bring you our conversation after a word from our sponsor.

Pat Skerrett
Welcome to the First Opinion Podcast. I'm Pat Skerrett, editor of First Opinion, STAT's platform for articles written by biotech insiders, health care workers, researchers and others with interesting or illuminating or provocative perspectives to share about the life sciences writ large. It's great to talk with you, Frank, and Anne.

Frank Lin [00:02:17]
Thanks for having us, Patrick.

Anne Madison

Thank you.

Pat Skerrett
So how did you two connect or meet?

Frank Lin
[laughs] So I am at John Hopkins and — along with my close colleagues like Carrie Nieman, who's also an ENT physician — for the last several years, we've been running a study throughout Baltimore called the Baltimore HEARS Study, which is basically a study for how we can deliver hearing care more affordably and accessibly in the community. Anne was one of our clear success stories very early on, having participated in our pilot, basically getting hearing care, direct from the community with a trained community health care worker, not even a physician or a direct audiologist. And since then, Anne has been one of our community health care workers who has herself now been delivering hearing care directly in the community to older adults in a much larger, randomized controlled trial, HEARS Intervention, which actually just finished up late last year.

Pat Skerrett
So, Anne, did somebody just come knocking on your door one day?

Anne Madison
Well, I live in a senior community and we have a person called the services coordinator. And she's basically a social worker. And someone from Hopkins got in touch with our services coordinator back when this was getting started. And so I was interested. The woman approached me because she knew that I was hard of hearing. And another woman and I became participants in that study. And that was way back — like 2014, I mean, it was a while ago — and got through that successfully and then went on from there.

Pat Skerrett [00:03:57]
Very cool. So at the time that somebody from Hopkins came knocking, had you already noticed you were losing some of your hearing?

Anne Madison
Oh yes! I guess I started early. I started in my 50s. Notoriously with the microwave — which is a story I tell a lot — it just simply stopped beeping for me. And it does not beep to this day. And I thought that it was broken and it wasn't broken. I was having hearing loss. So that's what started me down the path.

Pat Skerrett
Did that immediately urge you to take action or did you let things go for a bit?

Anne Madison
I filed it away. I mentioned it to my doctor at that point (my internist) when I went in for something else, but I didn't follow up on it. I don't know whether I was afraid to find out what was going on in my hearing. Or — he didn't follow up on it and I didn't follow up on it. So, it just lay dormant and got worse for a number of years.

Pat Skerrett [00:05:09]
You talked with someone from NPR in a very lovely story, and you mentioned that it sort of made your world shrivel. How did that happen?

Anne Madison
It did. My husband died in 2011, so just ten years ago this month. And after that, I began to have trouble with things like hearing at the movies, you know, going to the movies or going to church. I found myself talking to people, you know, conversing with people. And they would say something and I would just kind of go, "mhm hm!" And I remembered my grandmother doing that, who was hard of hearing. And so it came on gradually. And I think the catalyst was probably the loss of my husband, but it impacted all kinds of things. Watching TV — I got shy about having my television on because I had to turn it up, you know, so loudly. And moving into an apartment, I was afraid I was going to annoy my neighbors. So it was kind of like the lights going out one by one. Things I enjoyed, I wasn't doing as much anymore.

Pat Skerrett
That must have been frustrating.

Anne Madison
It was — it was depressing, is what it was. And kind of continued that way, so by the time the Baltimore HEARS study got hold of me, boy, I was more than ready. I'm, like, do whatever! Here I am, do whatever you want. You know, I'm more than happy to participate. And indeed, it was really helpful, I got to understand what was going on in my head, in my ears; I got to understand that I wasn't the only person that this was happening to, and I got to actually do something about it.

Pat Skerrett
Frank, is Anne's story a common one?

Frank Lin [00:07:16]
Patrick, unfortunately, yes. I mean, in my role, one hat I wear is as an ENT surgeon, where I still see patients every week. And the stories and the patients I see are rife with the same examples of, you know, gradually, slowly coming on and then noticing subtle things, missing words, missing

out on conversations, not likely going out as much. And the problem is, so often it's insidious. So some people, unfortunately, like to sort of blow it off, saying, “oh, it's not me. It's my wife mumbling at me all the time. It's not my problem.” And others just get gradually cocooned away, more and more. Hearing loss, it's one of those things. It's very much a normal process of aging. Essentially, nearly two-thirds, two of every three adults over 70, have a hearing loss.

And I think because of that, unfortunately there's this tendency to see it, since it's very much in some ways a normal process of aging, it hence must be an inconsequential part of aging. And that's the thought process that went on for many, many —I would say even decades — just until the last five, six, seven years with research. We've been leading here at Hopkins and many of our colleagues are just increasingly showing that hearing loss, while it's a normal process of aging, it is certainly not without consequence. And hence the research now linking things with hearing loss with dementia and other health care outcomes. I think any clinician in the field who has been taking care of patients with hearing loss, they sort of intuitively knew that was probably the case, because those are the stories we got all the time.

Pat Skerrett
But I think to listeners, a connection between hearing loss and other physical problems or mental problems is going to come as a surprise.

Frank Lin
Yeah, you know, Patrick, I think intuitively a lot of people want to think initially, “oh, of course, it's linked with things, let's say like dementia, for instance, because people are getting older.” But clearly, that's not very interesting. Right. That's like saying white hair is linked with dementia. Which, of course, it is in a way, but not in a causal way.

Pat Skerrett
[laughs] Yeah.

Frank Lin [00:09:14]
But increasingly, this is the big change in the last 5 to 10 years now. A lot of the research — that we've been leading and others around the world now — links, let's say, hearing loss with dementia. And importantly, we're understanding that hearing loss is just one of the many risk factors for dementia. But we're understanding it is arguably the dominant one. And the reason why we are understanding that now is because of the underlying mechanisms through which we now understand how hearing loss could impact dementia. When you can't hear well, it basically means your brain's constantly having to work a lot harder to decode that much more garbled sound. And that can take a toll on the brain. And that gets to the idea of what we call cognitive load or cognitive overload. Which is that your brain's constantly having to spend more energy

dealing with hearing when that energy could have been used to help protect against other things that lead to dementia like Alzheimer's disease. You know, that's one idea.

A second idea, which is related, but actually distinct, is the idea that hearing loss in and of itself, can actually trigger changes in terms of the brain structure and hence the brain function. Namely, if you can't hear very well, what we see now in people who have followed up for many, many years, is that parts of the brain literally shrink faster in those people with hearing loss versus those with normal hearing. And it gets to the idea that if you have sensory deprivation in those parts of the brain, those parts of the brain shrink faster. So, sort of like the colloquialism: use it or lose it.

And finally, the third most important idea for how hearing loss could contribute to dementia risk is something that Anne just mentioned herself — just the gradual process of being a little more isolated, a little more lonely. And, in turn now, we've long known that social isolation, remaining socially engaged, is hugely important for maintaining your cognitive health. So those three underlying pathways, there's a lot of evidence for, and yet no one — until just a little over the last 5 to 10 years — had begun really robustly studying whether or not hearing loss leads to a faster rate of dementia. And increasingly, all the studies now over the last 5 to 6 years have shown this. Such that, you know, just a few years ago, the Lancet Commission, which is one of the major medical journals around the world, published a major review and concluded that hearing loss is single-handedly the largest and the most dominant risk factor for dementia compared to all the other known risk factors like high blood pressure, diabetes, and things like that.

Pat Skerrett [00:11:29]
I think that's going to blow a lot of listeners' minds.

Frank Lin
Yeah, and, you know, I think it serves as a wake-up call. The really interesting thing about hearing loss is that from a public health perspective, we think that dementia is important —which, I think everyone feels dementia's important. [Laughs] And it's a really interesting risk factor because, first of all, hearing loss is really common. It's not a rare risk factor, one in a thousand. This is the majority of older adults. At the same time, it's a risk factor for which there are established interventions, namely things like hearing aids. And likewise, those interventions, namely hearing aids, come with no risk. There's no downside to using a hearing aid. And already, they're widely underutilized. So from a public health standpoint, I think that's why, all of a sudden, hearing loss is getting so much attention. Even from Congress nowadays, and from the National Academies, which is the subject of a STAT article, mainly because of just how important it may be as a public health target for us to really improve the lives of literally tens of millions of older adults. For an intervention that comes with essentially zero risk. It's not like

taking a risky drug or something like that. There is no risk, there's only positive upside. And we're increasingly understanding that the upside may be quite large, in fact.

Pat Skerrett
So Anne, it sounds like you were ready to embrace that upside when you first met the people from Hopkins. Had you wanted to get hearing aids before that?

Anne Madison
Yes. One thing I've found when you move into a community with older people, you get on two mailing lists: the hearing aids mailing list and the cemetery lots mailing list.

Pat Skerrett
[Laughs].

Anne Madison
So apparently, you're supposed to just go deaf gradually and die and be a profit center. But I would get those circulars, and I almost always would investigate, I would always make some inquiry. And, you know, the word would come back. In my case, they would always estimate somewhere between $4,000, maybe $4,500 for my hearing aids. And, you know, I'm at the point where I can't just whip out the Visa and say here, you know, put it on my charge. And easy payment plans are not so easy when you are on a tight budget, so it was just not possible. There wasn't any way I could do it. I couldn't even be irresponsible and do it. So. And my name is legion. I would bet you two-thirds of the people in this building are in the exact same boat.

Pat Skerrett
So, Anne, when you got your first hearing aids, were they the high-end ones that you and Frank are talking about, or were they something different?

Anne Madison [00:14:19]
They were something quite different. The devices that we used in Baltimore HEARS are relatively low in cost, and they are really not hearing aids. They're not recognized as hearing aids. They're called [coughs] excuse me, personal sound amplification products, which is a mouthful. And what it is, is a device that takes the sound and amplifies it before it gets to your ear while — in the case of the one that I got — enabling you to have some adjustments. Mine adjusts for everyday, restaurant (which is any situation where there's noise, ambient noise), and entertainment, it's called, which is kind of a surround-sound thing that you could use at a lecture or a concert hall or a movie or in church. And it has 10 volume levels. So you can get it pretty nicely adjusted. And it's not faultless, there are things about it to this day that annoy me. But I'm still using this device and I think if you wanted to buy one, I'm not sure how much it would cost you, but it would be closer to the $500 range than it would to the $1000 range. And they can help

a lot of people. They can't help everybody because there are all kinds of reasons people lose their hearing or are hard of hearing or are deaf. And, you know, they need to be worked with in some other way. But for people like me, who are just losing those nerve cells, dying off, they can be of a great deal of help.

Pat Skerrett
So they made a difference for you?

Anne Madison [00:16:22]
Yeah, I use it quite regularly. And I had been able to adapt some of its functions to other parts of my life. When I was still driving, I used to use the restaurant setting when I got behind the wheel because it helps you focus on the loud noises that you need to hear when you're driving, like sirens or whistles or whatever. So it's been very good for me and I'm not ready to give it up yet. I'll probably know when I am.

Pat Skerrett
Frank, you mentioned in your essay that Medicare long didn't cover hearing services or hearing aids. Is that part of the kind of perverse logic that our eyes and our ears and our teeth aren't really part of our bodies?

Frank Lin
Yeah, you know, Patrick, historically, I mean, it may be a segue to this idea. Why are hearing aids so expensive and how is Anne doing well with one that's colloquially not even a hearing aid, but at a lot cheaper value? So there are two things I understand that have currently set the stage for hearing care and Medicare, and why hearing aids are so expensive now. The first one, as you alluded to, is in 1965 when Medicare came to be with the Social Security Act. Back then, the way Medicare was designed was mainly to protect seniors from hospital expenses. So, the outpatient stuff wasn't really prioritized. Namely at that point, too, hearing aids weren't really fully available yet. There weren't really robust options to treat hearing loss. Hearing loss wasn't considered to be a priority by any means. People worried about other things back then. And instead, the only things that were covered were basically the diagnostic services of an audiologist — but none of the treatment services. Which, again, right now, it seems like a travesty. But admittedly, back then, it sort of made sense. So that's why to this day, audiologists can be reimbursed for doing testing. But sadly enough, they aren't covered to provide any treatment services around hearing loss. And it seems like a pretty bitter paradox, a bitter pill to swallow, that you can see us. You can see an audiologist and be told you have hearing loss and yet, do nothing about it.

Pat Skerrett

That means, let's say you're diagnosed with hearing loss. You go and get hearing aids and you need help figuring them out. The audiologist doesn't get paid for any of that work.

Frank Lin [00:18:50]
No, absolutely not. So audiologists get paid to do your hearing test and that's it. Not even to teach you about hearing, tell you what it means, how it could impact you, how to communicate better, anything around a hearing aid, zip, zero, none. The second other big piece of federal legislation which led to why hearing aids are still so expensive is in 1977, there was actually a joint congressional FDA task force which put together special regulations to regulate hearing aids. And the reason for that was throughout the '60s, early '70s, as hearing aids came to be, there was a lot of abuse. There were door-to-door salespeople literally going around selling hearing aids, which were honestly abusive. And they didn't work. It was rife with fraud. So the regulations in '77 put together by the FDA said that hearing aids as a medical device, which was appropriate, could only be essentially sold through a licensed provider and they couldn't be sold essentially over the counter. Which basically means that audiologists became the gatekeepers to hearing aids. The only way audiologists can make essentially revenue by helping someone hearing loss, they sell the hearing aids at a premium. Because they include all their services in there. At the same time, even the wholesale cost of hearing aids are high to audiologists because it's fundamentally a low volume, high margin business model. There are five hearing aid manufacturers which control about 90-95% of the world's hearing aid marketplace. Because it's a very constrained, gatekeeper model of a market.

Pat Skerrett
But I gather that's changing now since 2017 and more recent things. Can you explain that?

Frank Lin [00:20:19]
That's the exciting stuff, Patrick! It's two converging pieces of legislation, and one's already happened. One will hopefully happen over the next few months. They are both set to already correct those historical anachronisms' "injustice" now. But what's happened with that law that got passed in 2017 is that it requires the FDA to re-regulate hearing aids. Namely, to create a specific regulatory category for hearing aids that could be explicitly sold over the counter, directly to consumers, and does not have to go through an ENT like me or an audiologist, but will be sold directly to consumer, And for which those hearing aids will be regulated by the FDA for safety and efficacy. Namely, they would have certain performance standards on sound quality and maximal sound output. So, that law went into effect in 2017. It gave the FDA three years to do this because it's actually not easy to do this. The FDA actually blew through their deadline, unfortunately, in August 2020. They attribute it to Covid. But the exciting thing is that in June, actually, the FDA officially announced on their spring docket that they're going to release these regulations later this year. And that was coupled with, just a few weeks later, President Biden in a White House executive action ordered to basically improve competition economy. One of the

specific items that was called out in the executive action was requesting the FDA immediately release this in the next hundred twenty days. What this will allow then, is, let's say, next year, as these regulations finally go into effect, companies like Samsung, Apple, Bose will finally be able to, for the first time, make hearing aids and sell them directly to consumers.

Pat Skerrett [00:21:55]
So those companies are going to want to make a buck. Do you think they'll still be affordable for people, you know, so that Anne might take a trip to a local Apple store or Bose store and get a new pair without breaking the Visa card?

Frank Lin
Yeah, I certainly hope so. And the reason why I say I hope so — and I believe so — is because fundamentally, there's competition. The technology involved in a pair of AirPod Pros, or any decent of these earbuds hearables, is actually not that much different than a hearing aid, in terms of the actual component parts, sometimes. So let's say even if the AirPod Pros had to be twice the cost to make it more like a hearing aid, that makes it $500. Right. So I think, again, that's possible because of economies of scale. When you have a market, which is the consumers themselves, as opposed to a gatekeeper, namely an audiology ENT like me, who has to provide it, buy it, and then resell it to consumers. I think we're all relatively confident those costs will drop precipitously because of just the market scale and the competition.

Pat Skerrett
So Anne, instead of seeing predatory ads or circulars coming into your mail, let's say this sea change that Frank is describing happens. Would you be willing to go to an Apple store or a Samsung store and try out a new pair of hearing aids?

Anne Madison [00:23:11]
They would have to beat me off with a stick, I would be there. And I would be trying to decide which was better, the Apple or the Samsung. I have opinions on that subject [laughs]. I've spent some time thinking, actually — it's very entertaining — about: Are there ways that I could use a pair of earbuds and my phone to have, you know, two hearing devices and do better. In other words, could I carry this all around with me and use it when I need to hear something? I don't think so quite yet, but it certainly is good technology.

Pat Skerrett
So, you know, if there are any developers listening in, you just gave somebody a great idea.

Anne Madison
Oh, you bet I would. I would be lined up. I could tell you all about that. You know, I could spend an hour, so, we won't.

Pat Skerrett
And so, Frank, with these over-the-counter devices, Medicare won't be covering those, correct?

Frank Lin [00:24:17]
Yeah. So this is, you know, the second piece of major legislation, which is not a done deal like the over-the-counter hearing act of 2017. But which is hopefully inching closer. It's the inclusion, and changing Medicare now, to include actually hearing care service and hearing aids. So over the last few years — and as I said, that's essentially righting a historical wrong that was brought about 1965, which wasn't necessarily wrong back then. But now it's a bit of injustice. A big focus in this year's Congress, prompted by President Biden's budget request for fiscal year 2022, and which now has been championed by Chuck Schumer and and in particular Bernie Sanders, is the inclusion of hearing care service. My group and I have been advising the various Senate committees around this bill. So what Medicare would do, then, is: Medicare would begin covering hearing care services for anybody with hearing loss. Basically, the service of an audiologist to educate someone like Anne, to provide counseling, to say what kind of devices would you possibly need, where you are struggling with communication, to help provide unbiased guidance from audiologist. So those would always be covered. Then, if you had more of a mild to moderate hearing loss that would be served by OTC hearing aids, those people would buy their hearing aids on their own, which is possible. I mean, if a pair of Apple AirPods are $200, then you could buy your own Apple AirPods. But then, if you still need a service, you need someone to help you learn how to use it, how to use your phone, how to figure out which is the best device — you can still go see the audiologist. So the service would be covered. So you might buy the device on your own (possibly only a couple hundred bucks), but then the service will be provided.

Then if you have a more severe hearing loss, and some people have that. About 5% of people, older adults, have a more severe hearing loss that certainly would not be served by over-the-counter hearing aids. They're not powerful enough. Then Medicare, at that point, would begin covering the hearing aids, as well as the hearing care service. So much of the current legislation that has been proposed right now in the fiscal fiscal year 2022 budget bill, which was officially announced a few days ago in Congress and got passed by the Senate, would do exactly that. But that's the same framework that's now being proposed in this year's fiscal 2022 budget bill, which if advanced and actually passes in a few months — fingers crossed — that will be the sweet spot.

Pat Skerrett [00:26:35]
Anne, do you think if this kind of process had been available 10 years ago, you might have gotten hearing assistance earlier?

Anne Madison
Oh, I'm sure I would have. I'm sure I would.

Pat Skerrett
I'd like to close by asking both of you about the perception of hearing loss by people who have it and people who don't. People who need glasses rarely shy away from wearing glasses. But hearing aids seemed to be a completely different beast, as if there's some stigma attached to wearing them. Anne, did you feel like maybe you didn't want to use hearing aids because people would know, or you just didn't want to do it?

Anne Madison [00:27:18]
I never felt that way, personally. But I might be in the minority. I will actually tell you, whoever you might be, "I'm hard of hearing. Could you speak a little more slowly and distinctly?" A lot of people won't do that. There is a stigma. People feel it acutely. I've had clients who were afraid that their wife wouldn't think highly of them. I've had clients who were afraid, who were real solid church members — and there are a lot of people like that in this community — who didn't want to wear their new listening device to church, because the minister might think that it's like an MP3 player, and that they're not paying attention. And it was a real concern to this man. I mean, I felt terrible for him. And, you know, we finally decided what to do about it, but we talked about that for quite a while. So, yeah, there is a stigma. And people just don't want to face up to the fact that they've come to this point in their lives. So the people who came to us and actually showed interest and volunteered for the program were maybe a little bit unusual in that respect, because they were willing to make that jump to say, OK, I've got a problem, maybe these folks can help me. But we need to get to the place where everybody's comfortable saying, 'oh, I am a little hard of hearing. Could you speak up or speak more distinctly?'

Pat Skerrett
Frank, do you see people have an aversion to using a hearing aid, unlike an aversion to glasses?

Frank Lin [00:29:11]
Yeah, no, I think, Patrick, you're spot on. There's undoubtedly a stigma attached to hearing loss and hearing aids for so many reasons. It's not just one thing, for instance. Right. It has to do with a sense of getting old, the sense that you can't communicate as well, not wanting to be stigmatized with wearing the hearing aids, they look funny. I mean, there's so many reasons. But, you know, I think this is one really important idea, though, which we were so gung-ho and why I spent a lot of time being an advocate and, you know, ultimately testified before Congress for the over-the-counter hearing aid bill. Because that bill, when it goes in effect later this year and the regulations come out, that is a huge game changer. And the reason why I say that is as companies like Bose, Samsung, Apple begin making hearing aids, you know, you can guarantee — tongue-in-cheek, when Apple makes hearing aids, you know, it may look just like the Apple

AirPods Pro, right. So as you know, nowadays, I would say there's no stigma with wearing your Apple AirPod Pros around, everyone does that, right? So what's going to shift very rapidly, then, as these roll into the market is that: well, is that person wearing AirPod Pros? Or are those the AirPod Pros Plus with the hearing aid feature, for instance. It becomes one and the same.

Pat Skerrett
So in a quest to learn more about podcast demographics, I went looking the other day for the average age of podcast listeners. I didn't find that, but I did learn that three-quarters of podcast listeners are under the age of 55. Generally before they find themselves saying, " 'what?!' Or, 'could you say that again?!'" Over and over again during the day. So I hope that what we're talking about today is resolved when they start looking for hearing aids. Thank you both for joining us today. I've learned a lot and I hope that the road is being paved better and better for people with hearing loss.

Frank Lin
Thanks, Pat. It was an absolute pleasure.

Anne Madison
Thank you, Pat.

Pat Skerrett

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