

So this is Usher talks. And I want to say thank you to the Usher Syndrome Coalition for giving me the opportunity to present our latest article on Life strategies and facilitating factors when having deafblindness due to Usher syndrome type 2a. My name is Moa Wahlqvist. And I work as a researcher at the Audiological Research Centre, Faculty of Health and Medicine, Orebro University Hospital. This is a research department. So that is what we do on a daily basis.

I also work as a coordinator at the Swedish National Resource Center for Deafblindness in Sweden. And there, I work with issues that concern how to make research accessible for professionals in the field of deaf blindness and how to make knowledge sustainable over time. And I think this is something that we all struggle with over the world within this field.

Before I start, I want to acknowledge my colleagues and co-authors in this work. This study is part of Mattias Ehn's thesis work. Mattias is a clinical psychologist and a PhD student. And I also want to acknowledge Agneta Anderzen Carlsson, who is a registered nurse and associate professor. And she's the main supervisor for Mattias Ehn.

And then Claes Moller, who I guess some of you might know, is professor emeritus. So we have been working together on this study and in Mattias' thesis work.

On this slide, the aim of the study is presented. And what we wanted to do was to explore life strategies in people with Usher syndrome type 2a. How do they do? How do they handle everyday situations? And what do they think about it?

And on this next slide, I describe the methods that we have used in this study. And we have done explorative qualitative study design where we have used focus group interviews of or with 14 individuals with Usher syndrome type 2a.

And the participants were four women and 10 men. And they were aged from 20 to 64. They all had a moderate to severe hearing loss. The range was 48 to 52 decibels with a mean of 65 decibels. So they all used hearing aids and other technical devices but used spoken language.

They had a visual field range of two to five where the median was four, which indicates that you have around 5% to 10% of a visual field or five to 10 degrees of a visual field. The visual acuity range was from 0.05 to 1.0. 1.0 is perfect vision, visual acuity. And here, the mean was 0.4.

There were three focus groups, one with younger men from 20 up to 43 and then a group of older men from 44 and up to 64 then. And then we had one group of women, since that was only four participated. So they were all ages. The interviews were audio and video recorded and that we have used for transcription later on.

So this slide shows the setting. Actually, the interviews took place at a research event that we had here at the audiological research center. And people with Usher type 2a were invited to do different things at this event.

The focus group interviews were one of the activities. And this activity lasted for two hours with a break. But they also participated in cognitive tests and in measuring their hearing loss and so on. We also had some more presentations about what's the latest within the research and the social event.

But what about the focus group interviews then? I was the one moderating the interviews. And I had a senior researcher who was present in the room helping me out. And as I said previous, all participants used their hearing aids. And we also had a loop system in the room that they could use. And we had done some additional adjustments of the room. So we had put down window blinds to prevent from glare. And we checked that everybody could see and hear as good as possible.

The initial question to the group was, how do you cope with your life situation? And how do you manage difficulties? And if you were not successful in dealing with a situation, in what way would you have liked to do things? And then after posing this question, I am moderating, turn-taking, and helping out to indicate who was speaking next and so on. And then they were just discussing around this topic.

On this slide, I describe a little bit about the analysis of the transcribed interviews. So they were video and audio recorded and then transcribed. And then in the analysis process, we have used inductive content analysis and according to Graneheim and Lundman 2004.

And this has been a reflective interpretative process where we all have been involved discussing meaning units and what are they about, what are they talking about, what is the content, is there an underlying meaning of what they are saying or what they are talking about in this.

And this all resulted in that we identified 17 subcategories and seven categories, two latent sub-themes, and one superordinate theme. And as we move on, I will discuss some of these categories in the results.

So if we go into the results then, I will now present some of our findings and what were they saying about the strategies that they used. One of the sub-themes that we identified was resolving or preventing challenges. This could then further be divided in remaining active as it says on this slide, using devices is the next point, using support after that, and sharing knowledge.

When it comes to remaining active, this was only discussed in the group of the younger men. And this could also be further divided into adapting activities using memory and attention to have-- to use as a strategy in your everyday life.

On the next slide, I will give you some of the quotes from the participants when they were talking about this resolving or preventing challenges. On this slide, we can see a quote from one of the participants and when talking about how to remain active and keep up with business as usual. And I will read it out loud to you.

"I just want to be with my friends. I've said from day one that I will refuse to let it, the deafblindness, affect my life and prevent me from living the life I want. So then I just go with the flow, so to speak. And sometimes, one just sits there and can hear nothing because the music is so loud. But at the same time, one doesn't want to miss out on anything."

On the next slide, there is another quote from one of the participants when talking about receiving formal support and what that means. The participants also talked about informal support from family and friends. And that was something that they received. However, this was not unproblematic. And one of the participants said, it feels like I am a queen sitting there and waiting for my husband to serve me. And this was something that this person had to struggle with.

But this quote relates to more formal support. "I can be independent when I have a guide or interpreter or whatever. Then I'm independent. But if I don't have one, and I want to go shopping, then I become dependent on finding some shop assistant who will help me. And that's when I'm not independent."

The next slide, we have two quotes. Here, they are talking about sharing knowledge, both in terms of sharing knowledge with professionals, but also when you need to tell friends or family about your situation, or when a situation has changed. This sharing knowledge includes both informing in everyday situations and educating professionals. And this was experienced as the never-ending process to inform others about their situations to make life easier for themselves.

So now, I will read the first quote to you. "It is clear that you have to inform, as it makes it easier for others to comprehend if told how to handle it, the deaf blindness. It is not easy for them to understand because it doesn't show."

And the second quote relates to when you have to educate professionals. "Then after six or 12 months, there is a new official, which means that you have to educate an endless number of people. And it's the same when you meet doctors. It's so bloody hard." So again, this was something that you had to do. And they had strategies or ways to talk about or to inform about their deafblindness or their situation. But it was a never-ending story.

On this slide, I have the other sub-theme that we identified. And this we have called comforting oneself. It also can be divided into three different categories, which all represent different aspects of this sub-theme. And comforting oneself has more to do with the emotional aspects of participants' struggle to manage their life situation.

And the three categories within this sub-theme are to appreciate the present. And this deals with an uncertain future and encompasses the subcategories seize the moment and to enjoy meaningful activities. The next category we have called maintaining a positive image and has to do with aspects of self-confidence and identity.

And finally, elevating emotional pain has to do with strategies that the participant used to prevent themselves from intrusive thoughts and emotions. And this encompasses both self-distancing and escapism, as well as hope.

And on the next slides, I will read out some of the quotes within this sub-theme. On this slide, we can see one of the participants reflecting on the uncertain future and how to be present and enjoying life as it is now. "And today, there is gene therapy, as well as a lot of talk about stem cells and such. But I've thought about it for more than 30 years. And time just passes by without a cure. You have to enjoy life anyway. In my opinion, life must be good, or it's not worth living."

Within this sub-theme, people also talked about how they did to find these moments to enjoy life-- maybe taking a bath with a child, just being present in the here and now, lighting a lot of candles, and so on or enjoying a nice dinner with close friends at home and that this made them feel comfortable and enjoying their life as it is right now.

On the next slide, there are two quotes that relate to how to maintain a positive image. And here, the participants are reflecting on the sub-categories within this. The first one has to do with to negotiate who I am. And this was a strive to keep identity and not be defined by the progressive disease. Now, I will read it to you.

"My identity-- first and foremost, I have always had impaired hearing and not deafblindness. I have my interests and yours is music and so on. I guess it is our identities and our ways of spending time together with our friends. Then it is made more difficult by the fact that we have disabilities that are specific to the situation."

The second quote more has to maybe do with acceptance or this negotiating who I am and when things change, who am I then. "There are different kinds of acceptance. I accept the fact that I have Usher 2. But I still find it difficult to accept that my vision will deteriorate."

This quote on the next slide has to do with standing up for myself and showing who I am and who I want to be. And here, the person says, "There is no reason to feel ashamed about being in need of some help. I say you must not feel sorry for me. I said it's not me who is the problem. It's my eyesight that is so tiring because we, those with deafblindness, are just as capable as everybody else. We just have our own prerequisites."

The next slide has to do with the categories of elevating from emotional pain. And here is two quotes to exemplify self-distance and escapist that the participants talked about. So I'll read the first one. "For me, laughing is very important, I mean, seeing things in a different light. Some situations may not be a laughing matter, but you still laugh." And to use humor was expressed by several of the participants as a strategy to handle situations that were difficulties-- that were difficult.

The next quote has to do maybe with escapism. And here, the person says, "I'm also quite good at switching off. Then I let go, watch a film or play a TV game or whatever. That's my way of relaxing. I just switch off."

So that was the last quote that I had for you. When we looked at the material when we had gone through all these categories, the sub-themes and so on, as I said, we identified a superordinate theme. And we have called this being at the helm. And that has to do with the participants' active, cognitive, and emotional strive to be in control of the situations in life that they consider to be important for them.

And to find the way to describe this, we have used a model called the psychological flexibility model. And I guess something-- this is something maybe that we all are striving for. But for people with Usher syndrome, this becomes very important as the disease progresses and during life.

So on this slide, to conclude this presentation, what we have explored and described in the article is that the participants' express a variety of strategies to handle consequences of their deafblindness. By being at the helm, the participants' express a high psychological flexibility. And they are active agents in their lives. And this is very important-- they want to be in control. And they take control and are active in their lives.

If you want to read the whole article, it is available by open access. And you can search for it by searching for Mattias Ehn. And the article is published in an *International Journal of Qualitative Studies on Health and Well-being*.

And with that, in this last slide, I say thank you for the attention. And if you have any questions or want to reflect on something, don't hesitate to contact me. My email address is on this slide. And it says moa.wahlqvist@nkcdb.se. Thank you.