Life strategies and facilitating factors when having deafblindness due to Usher syndrome type 2a

Moa Wahlqvist

PhD Disability science

Researcher, Coordinator, Social worker

Audiological Research Centre, Faculty of Health and Medicine, Örebro University hospital, Swedish Institute for disability research, Örebro University,

The Swedish National Resource Center for Deafblindness,

Sweden

Co authors:

Mattias Ehn, clinical psychologist, PhD student[1,2]

Agneta Anderzén Carlsson, RN, PhD, Associate professor[1,3]

Claes Möller, PhD, professor emeritus[1,2]

Affiliations:

[1]The Swedish Institute for Disability Research, Faculty of Medicine and Health, Örebro University, Örebro, Sweden

[2]The Audiological Research Centre, Faculty of Medicine and Health, Örebro University hospital, Örebro, Sweden

[3]University Health Care Research Centre, Faculty of Medicine and Health, Örebro University, Örebro, Sweden

The aim

The aim of the study was to explore life strategies in people with Usher syndrome type 2a

Methods

Explorative qualitative study design with focus group interviews of 14 individuals with Usher syndrome type 2a.

Participants where 4 women and 10 men aged 20-64.
Moderate to severe hearing loss, range 48-80db (mean 65db).
Visual field range 2-5 (median 4)
Visual acuity range 0,05-1,0 (mean 0,4)

Three focus groups, audio and video recorded.

Setting

Research event

Focus group interviews, 2 hours with a break

Initial question:

“How do you cope with your life situation and how do you manage difficulties? If you were not successful in dealing with the situation, in what way would you have liked to do things?”

Analysis

Inductive content analysis according to Graneheim & Lundman (2004)

Reflective interpretative process involving all authors

Results

Resolving or preventing challenges

Remaining active,
Using devices,
Using support,
Sharing knowledge

I just want to be with my friends. I have said from day one that I will refuse to let it [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. (Person 6)

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 want to go shopping then I become dependent on finding some shop assistant who’ll help me. And that’s when I’m not independent. (Person 3)

It is clear that you have to [inform], as it makes it easier for others to comprehend if told how to handle it [deafblindness]. It is not easy for them to understand, because it doesn’t show. (Person 3)

Then after six or twelve months there is a new official. Which means that you have to educate an endless number of people. And it is the same when you meet doctors. It is so bloody hard. (Person 2)

Comforting oneself

Appreciating the present,
Maintaining a positive image,
Alleviating emotional pain

And today there is gene therapy, as well as a lot of talk about stem cells and such stuff. But I have 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. (Person 13)

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 way 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 (Person 8)

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 (Person 10)

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 is not me who is the problem, it is my eyesight that is so trying. Because we [those with deafblindness] are just as capable as everybody else, we just have our own prerequisites. (Person 4)

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. (Person 10)

I am 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. (Person 6)

Being at the helm

encompasses the participants’ active, cognitive and emotional strive to be in control of situations in life that they considered to be important for them.

Conclusion

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 are active agents in their life's.

Thanks for the attention!

moa.wahlqvist@nkcdb.se

ÖREBRO
UNIVERSITY

Region Örebro County