

Current research and previous studies

The importance of interdisciplinary studies in health and Usher syndrome

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Outline for the presentation

Previous studies

Health and people with Usher syndrome

Health, work and people with Usher syndrome type 1 and 2

Ongoing studies

Strategies in life for persons with Usher syndrome type 2a

Lived experiences of work and health in persons with Usher syndrome type 2

Health and family life in families where one parent has deafblindness

Health and people with Usher syndrome

Overall aim was to describe health of people with Usher syndrome



The Swedish Usher register

Swedish National Register including individuals with Usher syndrome

All three types included

Audiograms and visual test

Genetic diagnose

The Swedish health questionnaire "Health on equal terms"

Hospital Anxiety and Depression Scale

Reference population

The Public Health Agency of Sweden

A cross section of the Swedish population

Includes individuals with and without impairments

Participants

	Reference	USH1	USH2	USH3
Number	5738	60	96	15
Age mean (years)	49	49	55	41
Age (min-max)	16-84	20-79	18-84	19-71
Women	56%	60%	53%	71%
Clinical diagnose		60	96	15
Genetic diagnose		43%	59%	73%
Mean HL		99 db	73 db	99 db
Mean Visual acuity (1,0-0,0)		0,5	0,4	0,7
Mean Visual field (1- 5)		3	4	3

Results

Poor
physical
health

Poor
psychological
health

Social trust

Financial
situation

People with USH regardless of clinical type, and in comparison with a cross-section of the Swedish population, report problems with physical and psychological health, lack of social trust and a strained financial situation.

A biopsychosocial perspective is needed when describing the health of people with Usher syndrome otherwise there is a risk of reducing the complexity and the consequences of living with deafblindness.

Work and Health in persons with Usher type 1 and 2

The aim was to describe relations between work and health in persons with Usher syndrome type 1 and 2

Participants

Usher type 2

Working group 34 individuals

Disability pension 33 individuals

No differences in hearing or vision

Slightly more women in both groups

Usher type 1

Working group 23 individuals

Non working 24 individuals

43% women working group and 63% non working group

No differences in hearing or vision

Reference population

Results Usher type 2

Significantly more psychological health problems reported from the individuals with disability pension.

Physical health did not present with the same pattern.

Results Usher type 1

The Usher non working group (and the reference non working group) reported to have more problems with psychological and physical health problems as well as problems with ADL than did the working groups.

Problems with social trust was more pronounced in the Usher type 1 non working group, except for being offended where persons with Usher type 1 who worked reported more problems.

Financial situation

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

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.

Preliminary results

- Resolving or preventing challenges
- Comforting oneself

Resolving and preventing challenges

It is about being able to have the imagination to find new ways, not being blind to the fact that there is more than one way...for example you may not need to hammer in nails when you can use a screw driver. (Person 14)

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)

Comforting oneself

So I feel that you have to do what you are capable of when you are capable of it, then you get the most out of activities you want to do. That's what I believe anyway. (Person 1)

It is like when I share a bath with my daughter, then we light a lot of candles, which she really loves. And then you relax and sort of feel content and in the here and now. Because then you are blissfully unaware of your problems, even though they still exist. (Person 2)

Being at the helm

The participants are committed agents in a process of striving to live a active life in accordance with their own values

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.

Ongoing and upcoming studies

- Lived experience of the relation between health and working life of people with Usher syndrome type 2
- Health and family climate in families where a parent has deafblindness
- Update of the health and people with Usher syndrome
- Experiences of support given in rehabilitation/habilitation settings for adults with deafblindness

Thanks for the attention!

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