

Usher Syndrome Coalition | Being a Child with Usher Syndrome, Bettina Kastrup Pedersen

Welcome to this presentation. I want to say thank you to the Usher Syndrome Coalition for giving me the opportunity to speak about a project two organizations in Denmark have been collaborated around. On slide number 2, I'd like to introduce myself. My name is Bettina Kastrup Pedersen. I work as an educational consultant in a public organization called Area of communication and special education.

My department is called ISHD, short for Institute for Vision Hearing and Deafblindness. And it is located in Aalborg in the northern part of Denmark. We provide advice to children with both acquired and congenitally deafblindness and to their network. We also give advice to adults with congenital deafblindness. I'm also a member of the Dbi Usher Network.

On slide number 2, I'll tell you the name of the project and who's been involved in the project. The title of the project is Being a child and young with deafblindness due to Usher syndrome. The project has been a collaboration between educational consultants, psychologists, psychology students, and communication consultants from CFD and ISHD. CFD provides advice to adults with acquired deafblindness and is a private organization.

On slide number 4, I'll describe the aim of the project. The project that we have made focused on what it generally means to live with Usher syndrome as a child and a young person. Before starting the project, we had some ideas of the outcome of the project.

We saw different ways of coping with the dual sensory loss in our daily work. And some of the children and young persons were struggling in their daily lives. And some of them were more vulnerable than others. What we wanted to do was to qualify the counseling we give to children and young people with Usher syndrome and through their network.

We found that a literature review had to be done in order to see what others had found on the topic about Usher syndrome. We wanted to produce an interview guide, interview guidelines, and to make interviews based on findings in literature and our own knowledge.

We wanted to write articles about some of the findings that we had made both in our daily work and in the literature review. And we also wanted to write a book that described what we found was necessary knowledge for people connected to the group. The booklet should also provide an insight into what challenges that children and young people have and what attention points networks around

them should face.

On slide number 5, I'd like to tell you a little bit about the literature review and the aim of it. There has been a preliminary literature research aimed. And the search aimed at uncovering various protection and vulnerability factors associated with living with Usher syndrome. The literature search revealed that living with a progressive loss of sense of sensation can make the individual more mentally and socially vulnerable.

There are few qualitative studies focusing exclusively on children and young persons with Usher syndrome. So the children and young people considerations from a study we made therefore contains an extremely valuable knowledge that can be applied in the future. And the aim of the review was to illustrate and to identify biological, psychological, and social vulnerabilities following Usher syndrome in the existing literature.

And in preparation of the interview study-- and here we used the knowledge from our daily work when we created the guidelines. Our aim was also to gain knowledge on protective factors that practitioners should be aware of when supporting persons or young people and children with Usher syndrome. And in the review, we used 29 quantitative and qualitative studies.

On slide number 6, I'll mention some of the results from the interview. The review revealed that biological, psychological, and social factors can function both as risk factors and protective factors. So we have to bear this in mind.

We found out that there were great variation in how vulnerable the individual felt. And we were curious to find out what the variations were grounded on, why there were differences where it was connected to. We found that there was a need for qualitative studies to focus on a more narrow sample with a younger population.

On slide number 7, I'll try and describe the aim of the interview guide that we made. Prior to the study, an interview guide was prepared based on experience and the initial literature search. And seven children and young people aged 13 to 29 were interviewed. The aim of the interviews was to make an investigation on how young people experience every day growing up with Usher syndrome.

On the next slide, on slide number 8, I'd like to mention the methods that we used in the interviews. We had seven interviews completed. It had six females and one male included. And the reason why we only had one male included was that it was very difficult for us to find young males that were interested in having an interview made.

Each interview lasted 40 to 128 minutes. And the age median was 18 years. We used a semi-structured interview guide based on practitioner's experience, on literature review, on bioecological model of human development by Bronfenbrenner, and by a biopsychosocial model from Engel.

The interview questions were prepared in a way that fit the age of the informers. The informers under 18 were questioned by one of the two consultants from ISHD who were part of the project. The informers over 18 were interviewed by a communication consultant from the project and from CFD. In analyzing the interviews, we used a qualitative content analysis from Hsieh and Shannon and a thematic analysis from Braun and Clarke.

And on slide number 9, as you can see, we had 10 themes identified reflecting the main considerations from the young people growing up with Usher syndromes.

And the 10 themes were the discovery of Usher, to meet others with Usher or deafblindness, the future with Usher, the feeling of being different from peers, consequences of double sensory loss physical as well as mental, support from family, friends, and professionals, relations, family, friends, and network, own understanding of Usher syndrome, recognition and knowledge, education and work when you have a diagnosis, and the last one, Usher management strategies.

All of the themes are discussed in relation to Antonovsky's salutogenic theory and the life change model. It is the first qualitative study to focus solely on young people with Usher syndrome. And future studies could emphasize certain themes and concentrate on specific groups or types of Usher syndromes.

The next slide, slide number 10, will mention two articles that we have made. Two articles have been written. And both are waiting to be published. One of the articles are highlighting the interview study, the background, the methods, and the key findings. And it has been written for *Deafblind Review* and will be in English.

Another article is focusing on the separate theme that we have named Feeling of otherness from the interview study. Besides having an empirical focus from the accounts of young people, it focuses on more theoretical aspects of feeling different than peers. This article is expected to be published in a Danish magazine for teachers or practitioners helping children and young people with special needs.

One of the ideas we had was also to create a booklet. And slide number 11, on slide number 11, I'll mention what is in this booklet that is almost finished. It will be published in this summer 2020. And of course, it is a result of the project. In the booklet, five particularly important themes are selected.

And they are described in the booklet.

The themes are the consequences of double sensory loss, physical and mental, the feeling of being different from peers, the support from family, friends, and professionals, strategies on how to master life adjustments, education and work when you have a diagnosis.

The reason why these are selected is that they seem to have a great significance in the answers from the informers. The themes contain a wide range of perspectives on living and growing up with Usher syndrome, which can be applied by professionals working with deafblind individuals.

The group behind the project want the booklet contribute to a greater understanding of how it feels to live with a progressive and in many ways slightly invisible functional impairment. It is our wish to let the booklet help support to the group, their families, and network. We intend to translate the booklet into English as soon as possible.

On slide number 12, I'd like to address the future directions or implications that can be made upon the topic based on what we have found. By discovering and identifying the needs of young people living with Usher syndrome, the project provides practitioners with some fundamental knowledge which need to be integrated in their everyday work. Knowledge concerning the environment and families around the young persons with Usher might be useful in shaping interventions.

The booklet and the articles are published in English in order to provide accessibility for more countries. The interview guide has been translated by Usher Kids Australia in order to share common knowledge and collaborate.

And the reason why it was possible to have this interview guide translated into English was, actually, it started in the Dbi Usher Network where I mentioned that we were having this project and that we have finished some interviews and that we have made this interview guide.

And then Emily Shepard from Usher Kids Australia was interested in trying to use the interview guide in Australia in order to see if there are similarities or differences from the Danish population. And actually, in the Usher Dbi Network, we think that it could be very interesting if somehow we could distribute this interview guide if someone is interested in collaborating and sharing knowledge.

Because as this group is very small, it is very necessary for all the people working around the group to share the knowledge that we have in order to help these children and young people more or better ways to cope with their daily lives growing up.

And I also think that it could be a good idea that if anyone is interested, they could also go into the Dbi website to the network and maybe write something about what they think.

And on the last slide, I just want to thank you all for the attention. And I have written my contact informations. And please feel free to contact me if you need more information or if you are interested in some kind of collaboration.

For me, myself, and for the group, the project group that I've been working with, and also for the Dbi Usher Network, it is of great importance that we somehow try and share the knowledge that I'm sure is available all over the world. Because if we do this, I'm sure that it would be very helpful for the children and for the young persons in their daily life. Thank you so much for listening.