



Being a child/young with Usher syndrome

USH2020 CONNECTIONS WEEK



REGION NORDJYLLAND
– i gode hænder



PRESENTER

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PROJECT

- 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.



AIM OF THE PROJECT

- Qualify the counseling we give to children and young people with Usher syndrome and their network.
- Litterature review.
- Interviews based on findings in litterature and knowledge.
- Articles.
- Booklet.



LITERATURE REVIEW

- Aim:
 - To illustrate and identify biological, psychological and social vulnerabilities following Usher syndrome in the existing literature.
 - In preparation of the interview study.
 - To gain knowledge on protective factors that practitioners should be aware of when supporting persons with Usher syndrome.
- 29 quantitative and qualitative studies were used.



- Results:
- Biological, psychological and social factors function as risk factors and protective factors.
- Great variation, in how vulnerable the individual felt.
- Need for qualitative studies to focus on a more narrow sample with a younger population.



INTERVIEWS

- Aim:
- An investigation on how young people experience everyday growing up with Usher.



METHODS:

- 7 interviews – 6 females and one male; 40 to 128 mins.; age median was 18 years.
- Semi-structured interview guide based on practitioners experience, literature review, bioecological model of human development (Bronfenbrenner, 1994) and biopsychosocial model (Engel, 1980)
- Qualitative Content Analysis (Hsieh & Shannon, 2005) and Thematic Analysis (Braun & Clarke, 2006)



RESULTS.

10 THEMES WERE IDENTIFIED REFLECTING THE ACCOUNTS OF THE YOUNG PEOPLE GROWING UP WITH USHER SYNDROME:

1. The Discovery of Usher
2. To meet others with Usher or deafblindness
3. The future with Usher
4. The feeling of being different from peers.
5. Consequences of double sensory loss - physical as well as mental
6. Support from family, friends and professionals
7. Relations. Family, friends and network.
8. Own understanding of Usher. Recognition and knowledge
9. Education and work - when you have a diagnosis
10. Usher management strategies.



ARTICLES

2 articles have been written – both are waiting to be published.

- One article highlighting the interview study, the background, methods and the key findings for DbI review.
- One article focusing on the separate theme 'Feeling of otherness' from the interview study. Besides having an empirical focus from the accounts of the young people, it focuses on more theoretical aspects of feeling different than their peers. Expected to be published in a danish magazine for teachers or practioners helping children or young people with special needs.



BOOKLET. 5 THEMES

- The consequences of double sensory loss - physical and mental.
- The feeling of being different from peers.
- The support of family and friends and professionals.
- Strategies on how to master life adjustments.
- Education and work - when you have a diagnosis.



FUTURE DIRECTIONS OR IMPLICATIONS

- 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 person with Usher might be useful in shaping interventions.
- The booklet and 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.



THANK YOU FOR THE ATTENTION.

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