Health and People with Usher syndrome

av

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Akademisk avhandling

Avhandling för medicine doktorsexamen i Handikappvetenskap,
som kommer att föras offentligt fredag den 13 november kl. 13.00,
Prismahuset, Hörsal 2, Örebro universitet

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Abstract


The present thesis concerns people with Usher syndrome (USH) and their health. People with USH have a congenital hearing loss of various degrees and an eye disease with a progressive course; for some, the balance is also affected. Three clinical groups have been identified 1, 2 and 3, and 13 genes have currently been identified. USH is the most common cause of deafblindness. Clinical knowledge and the limited research that exists have shown that people with deafblindness can experience difficulties in everyday life. Depression, anxiety and social withdrawal have been described.

The general aim of the present thesis was to describe the health of people with USH. The empirical material employed was based on an extensive survey in which people with USH answered two questionnaires concerning health, anxiety, depression, social trust, work, health-care, financial situation, and alcohol and drug use. The focus of the present thesis is on general health, physical health and psychological health, social trust and finance. Three studies in the present theses focus on USH1, 2 and 3, respectively; finally, the fourth study provides an in-group comparison of people with USH. The results of studies I and III are compared with a cross-section of the Swedish population. The results revealed poor physical and psychological health, a lack of social trust and a strained financial situation regardless of clinical diagnosis. The discussion stresses the importance of taking a biopsychosocial approach when describing the health of people with USH, in which previous research is lacking. Additional research should focus on the mechanisms at different levels that affect people with USH and their health from a life-course perspective. Furthermore, research should include a salutogenic perspective to explore the resources and strengths of people with USH.

Keywords: Usher syndrome, Deafblindness, Health, General Health, Physical Health, Psychological Health, Social Trust, Financial Situation

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