Life Strategies, Work and Health in People with Usher Syndrome

av

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Akademisk avhandling

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Abstract


Introduction: People with Usher syndrome (USH) have an inherited disorder causing congenital deafness or hearing loss combined with progressive vision loss and, in some cases, balance problems. Previous research has shown that people with USH have poor physical and psychological health. Research has, however, demonstrated that there are in-group health differences that have not yet been explored and that there is a lack of studies on life strategies as well as health in relation to working life.

Aim: The aim was to explore the relationship between work and health in people with USH1 and 2 and to explore the experiences of life strategies in people with USH 2.

Methods: A quantitative and a qualitative explorative design was employed comprising two cross-sectional studies of the relationship between work and health in people with USH2 (n=67) and USH1 (n=47). The third study, of life strategies, comprised focus group interviews with people with USH2a (n=14) analyzed by content analysis. The fourth study explored the lived experiences of working life by interviewing people with USH2 (n=7) using an interpretative phenomenological approach.

Results: Study 1 and 2 demonstrated significant differences in health between working and nonworking people. Nonworking people showed significantly poorer health. In study 3, a variety of strategies to prevent and resolve challenges in life, as well as to comfort oneself, was identified. The lived experiences of working life in people with USH2 (study 4) disclosed feelings of satisfaction, striving towards a work life balance. Work also disclosed feelings of limitations and uncertainty about the future.

Conclusion: The results, which are discussed in relation to the Meikirsh model of health, demonstrated a complexity. Individual life strategies, psychological flexibility and environmental aspects, such as social determinants have to be considered to receive a comprehensive picture of the relationship between work and health in people with USH. This thesis provides new insights into the health of people with USH.

Keywords: Deafblindness, health, life strategies, lived experience, Usher syndrome, work

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