

# Quantitative and qualitative methods when studying health in people with Usher syndrome

Mattias Ehn leg. Psychologist / Ph D  
Counselling & support for people with Deafblindness, region Stockholm.  
Department of Health sciences, Örebro University  
Audiological research centre, Region Örebro

# Usher syndrome

## Clinical subgroups

### Type 1

Profund Deafness

Progressive visual loss

Congenital loss of vestibular function

### Type 2

Congenital moderate to severe hearing loss

Progressive vision loss

### Typ 3

Congenital progressive hearing loss

Progressive vision loss

Progressive loss of vestibular function



Tonåren



20 – 30 år



30 – 40 år

# Health problems in people with USHER syndrome type 2?



- How can we explore health?
- Differences compared to the Swedish population? (Wahlqvist et al 2013).
- What is the relation between work and health in people with USH?



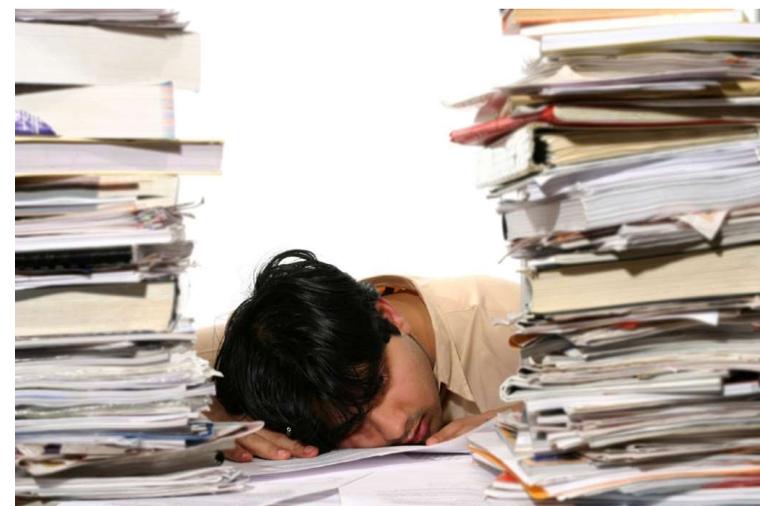
# Quantitative Methods

**Design: Quantitative explorative**

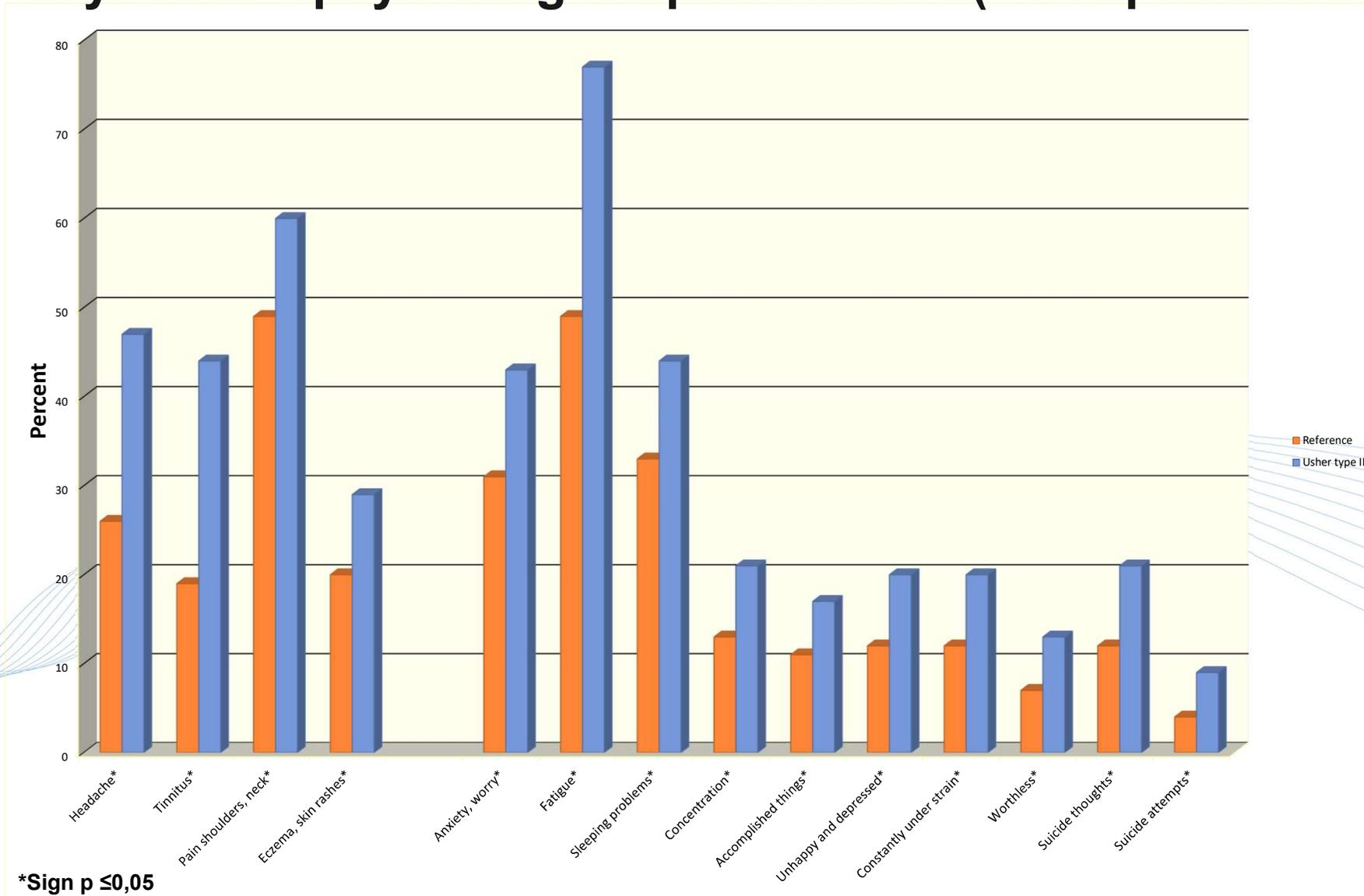
**Participants: 96 persons, (>18 years)  
34 working and 33 non-working (disability  
pension) aged 18-65 years.**

**Data collection: Register data, Public health  
questionnaires.**

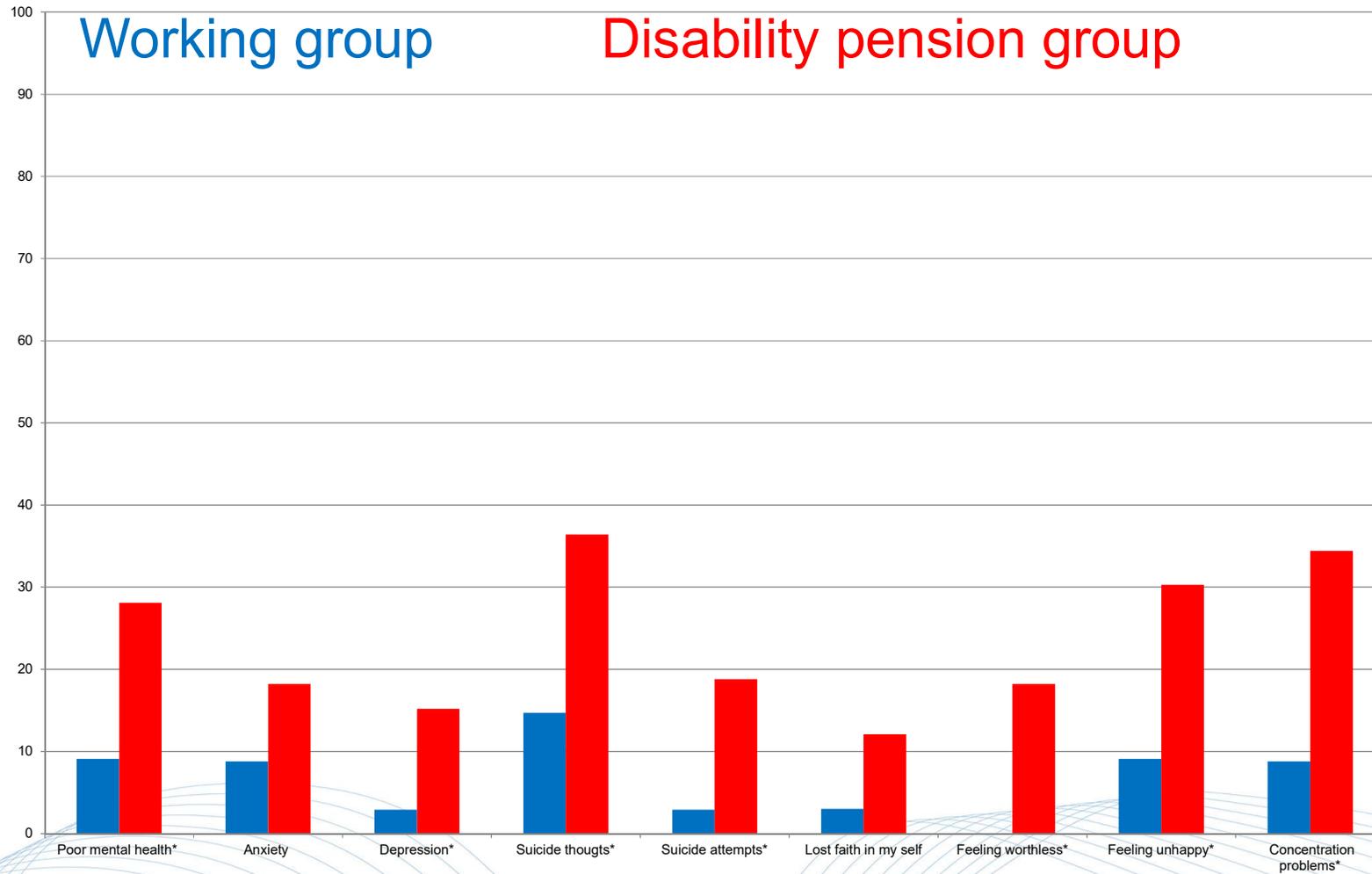
**Analysis: Non parametric Chi-2 testning,  
Multiple logistik regression analysis.**



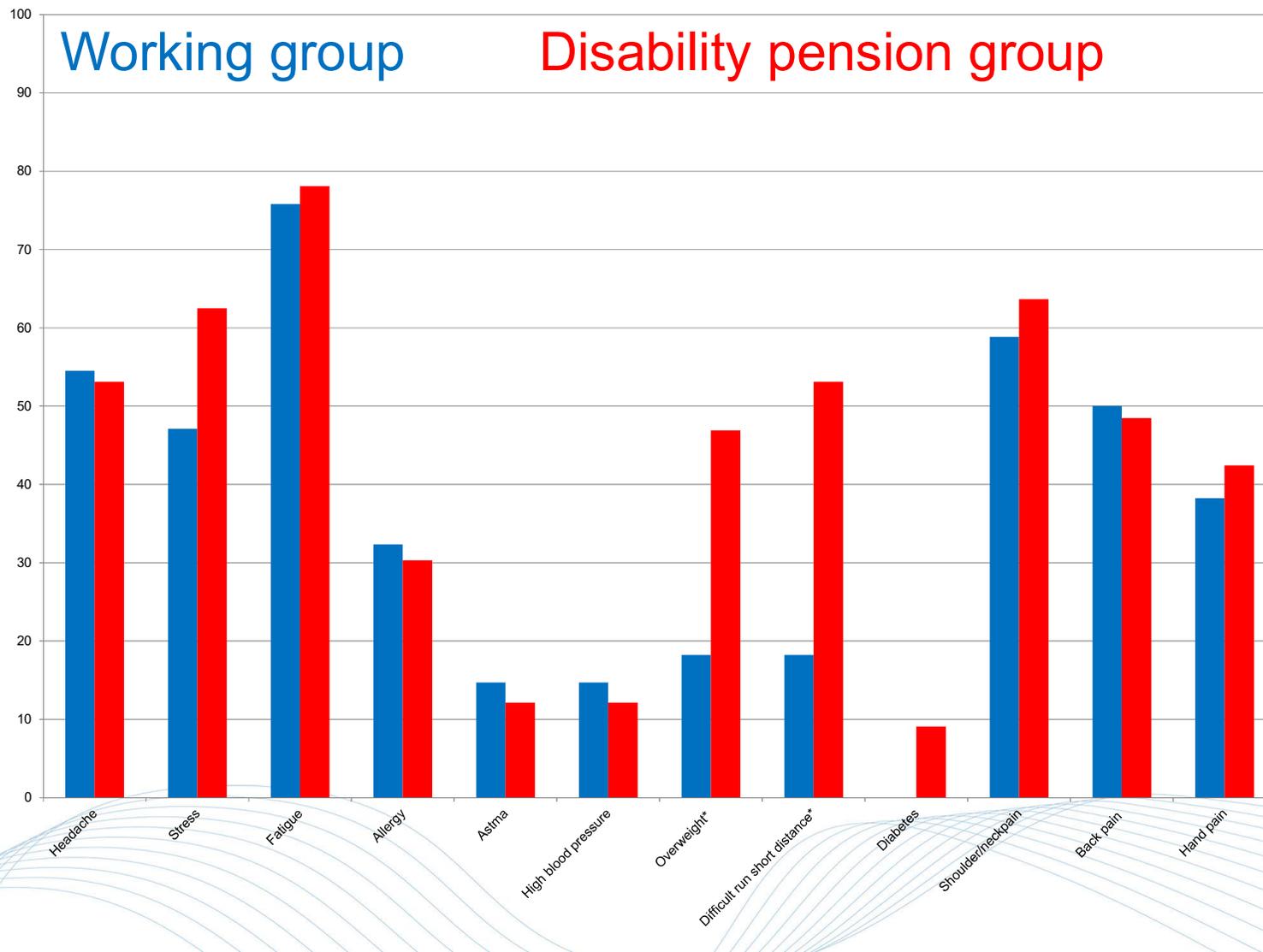
# Physical and psychological poor health (Wahlqvist et al 2013)



# Psychological health USH 2



# Fysical health USH2



# Conclusion of quantitative studies



**Statistically significant differences.**

**Physical and psychological health differences.**

**Work active correlates with better psychological health. No statistical differences in physical health.**

**How can we understand the high levels of fatigue?**

**Further studies are needed!**



# Fatigue

**Extreme tiredness that is not possible to recover after sleep or a few days of rest .  
extreme tiredness resulting from mental or physical exertion or illness.**



# Qualitative study

**What are the lived experiences of working life in people with Usher syndrome type 2?**



# Qualitative methods

**Design: qualitative explorative**

**Participants: 8 persons age 35-50 years (working 50-100%)**

**Data collection: individual semistructured interviews**

**Analysis: Interpretative phenomenological analysis**



# Themes



**Feelings of satisfaction**

**A commitment that needs balancing**

**Facing limitations – exhaustion Fatigue!**

**Feelings of uncertainty,**



# Triangulation?

- **Complementary**
  - **Cross checking**
  - **Enhance validity - trustworthiness**
  - **Complementary - richer picture**
- 
- **The use of multiple methods enable a broader and deeper picture of health in people with Usher syndrome.**

# Meikirch healthmodel (Bircher & Kuruvilla )



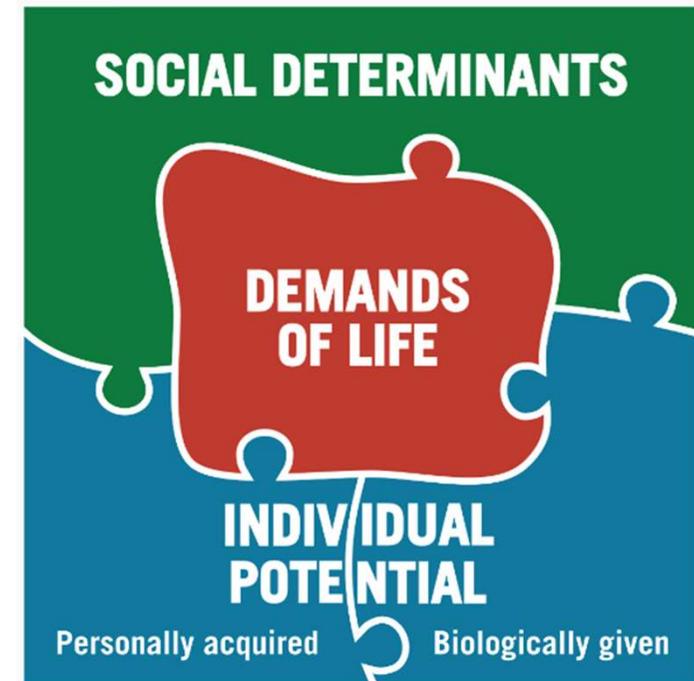
# Conclusion in a Health model

**Biologically given potentials** vision & hearing.

**Personally acquired potentials**, i.e. life strategies.

**Demands of life** – working life.

**Social determinants** – networks, education, rehabilitation, labor market.



## Litterature:

Wahlqvist, M., Möller, C., Möller, K., & Danermark, B. (2013). Physical and psychological health in persons with deafblindness that is due to Usher syndrome type II. *Journal of Visual Impairment & Blindness*, 107

( 3 ) , 2 0 7 – 2 2 0 . <https://doi.org/10.1177/0145482X1310700305>

Ehn, M., Möller, K., Danermark, B., & Möller, C. (2016). The relationship between work and health in persons with Usher syndrome type 2. *Journal of Visual Impairment & Blindness*, 110(4), 233–244. <https://doi.org/10.1177/0145482X1611000403>

Ehn, M., Wahlqvist, M., Möller, C., & Anderzén-Carlsson, A. (2020). The lived experiences of work and health of people living with deaf-blindness due to Usher syndrome type 2. *International Journal of Qualitative Studies on Health and Well-being*, 15(1), 1846671.