

Quality of Life and Loneliness among Patients with Ataxia in Denmark

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Background and Rationale



Rarity and Lack of research

- There are approximately 300 individuals with various forms of spinocerebellar ataxia in Denmark.
- The rarity of ataxia has resulted in limited focus, leaving a need for more research.



Impact on Health

- Ataxia can lead to shorter life expectancy and reduced quality of life.



Importance of Quality-of-Life Data

- Knowledge about the quality of life of various patient groups is essential for resource prioritization.
- The measure used, both nationally and internationally, is quality-adjusted life years (QALY) measured by EQ-5D-5L.



Loneliness as a Key Issue

- Loneliness is a particular issue, as many experience social exclusion.

Aim

This project has two aims

- The primary aim of the study is to estimate the quality of life of a representative study population of Danish patients with ataxia and HSP. Quality of life will be assessed using EQ-5D-5L questionnaires, which will be distributed by the Ataxia and HSP Association.
- The second aim is to explore and describe loneliness in this representative study population of Danish patients and to analyze the association between loneliness and quality of life. Loneliness will be assessed using the UCLA-questionnaire.

Design and Methods

Data collection

- Data will be collected through a survey.
- The questionnaires will be distributed via the Ataxia and HSP Association in Denmark.

Questionnaire content

- Background information about the patient (gender, age, marital status, region, which disease they have (ataxia/HSP), and, if known, their genetic mutation)
- The EQ-5D-5L questionnaire
 - A generic instrument developed to assess health-related quality of life.
 - Measures quality of life across five domains.
- The UCLA Three-Item Loneliness Scale
 - A validated and established tool for measuring loneliness

Analysis

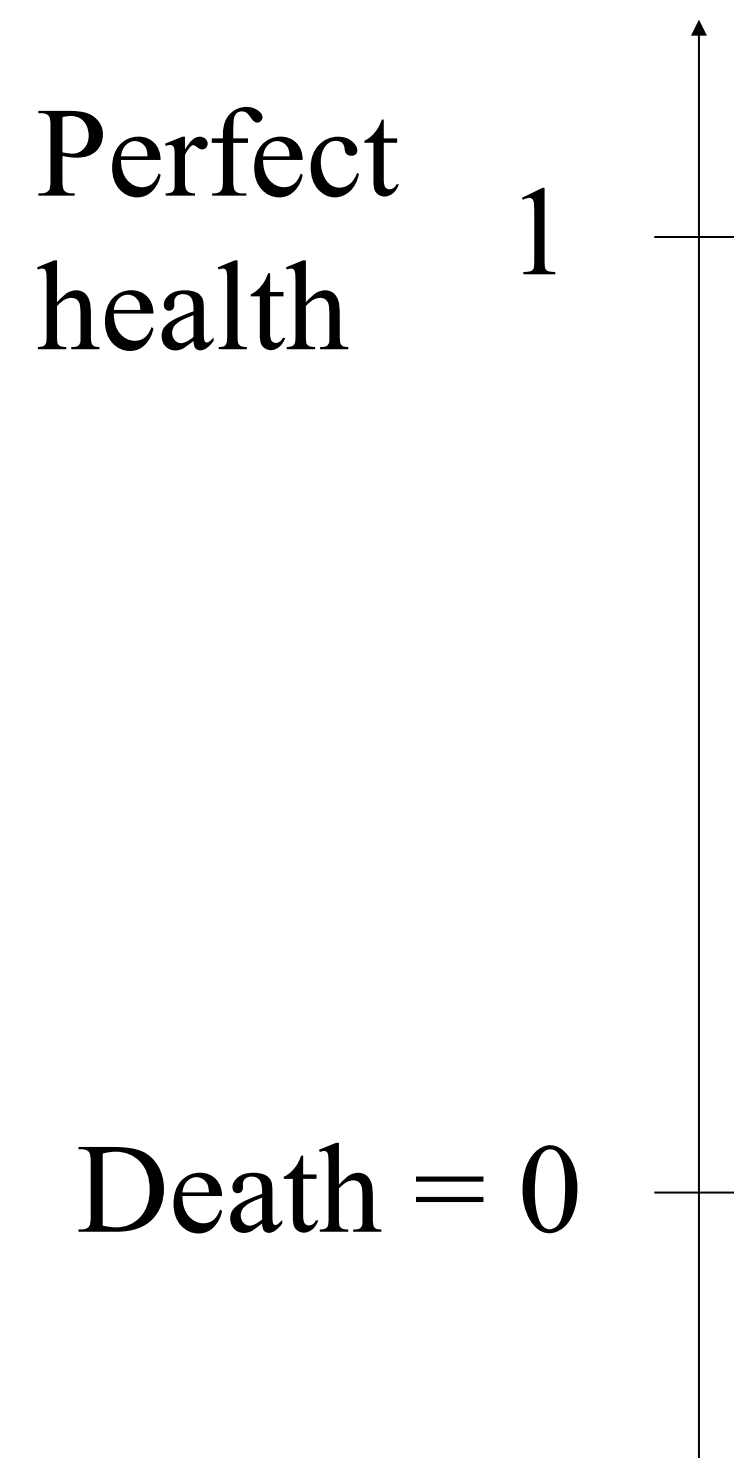
- Descriptive analysis: Based on various demographic characteristics, along with a comparison to the general population.

Why is EQ-5D-5L important?

- Knowledge of patients' quality-of-life measured with the EQ-5D-5L instrument is used throughout Europe for prioritization of new treatments:
 - To estimate 'value for money' of new treatments
 - Health Technology Assessment (HTA) including a cost-utility analysis (i.e. cost-per-QALY-analysis)
 - To estimate 'burden of disease'
 - Depending on the country, this may impact "Willingness-to-pay"

What is EQ-5D-5L?

- EuroQol- 5 Dimensions – 5 Levels
- All combinations of answers can be translated to a number between -1 and 1 (QALY-weight)



Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN/DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY/DEPRESSION

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

What is the UCLA?



UCLA 3-Item Loneliness Scale

1. How often do you feel that you lack companionship?

Hardly ever		1
Some of the time		2
Often		3

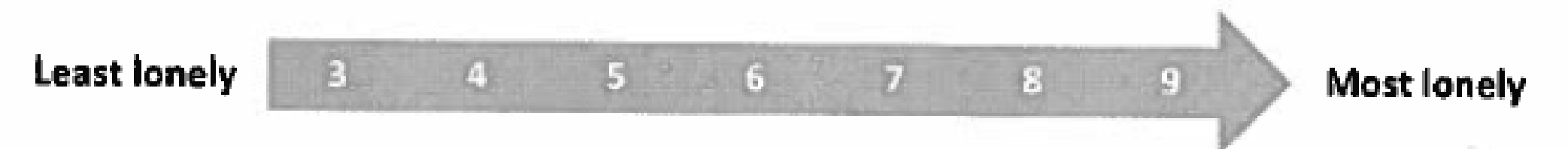
2. How often do you feel left out?

Hardly ever		1
Some of the time		2
Often		3

3. How often do you feel isolated from others?

Hardly ever		1
Some of the time		2
Often		3

The scores for each individual question can be added together to give you a possible range of scores from 3 to 9. Researchers in the past have grouped people who score 3 – 5 as “not lonely” and people with the score 6 – 9 as “lonely”.¹⁹



Summing up

The quality of life of patients with ataxia and HSP is sparsely covered in the international literature and has not been studied in Denmark.

The project will bring more knowledge about

- quality-of-life in patients with ataxia and HSP measured by the EQ-5D-5L instrument (QALY-weights)
- loneliness in patients with ataxia and HSP measured by the UCLA instrument
- correlation between EQ-5D-5L and specific issues of loneliness faced by this patient population

Knowledge of EQ-5D-5L in patients with ataxia and HSP can be used in national decision-making and prioritization)

*Thank you for the
opportunity to
present*

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