

COVER PAGE

Official title: The perceived quality of life in adult patients with inherited ichthyosis: a qualitative interview study

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Written description of the clinical study

Study objectives: The aim was to gain insight into the perceived impact of ichthyosis on the quality of life (QoL) of adult patients using the biopsychosocial model.

Study design: We conducted a descriptive study using individual semi-structured interviews. Perceived QoL was investigated and the biopsychosocial (BPS) model by Engel *et al.* (1977) was used as a guiding framework to construct the interview guide.

Methods: Patients ≥ 30 years of age and a molecular diagnosis of inherited ichthyosis, excluding ichthyosis vulgaris, were purposively recruited at a medical specialized center for genodermatoses in Maastricht and through the Dutch ichthyosis patient association to achieve broad recruitment resulting in a varied population. Semi-structured interviews were used to collect data. All interview data was recorded, transcribed, and analyzed using an inductive and reflexive thematic content approach.

Supporting Information

Appendix S1. Interview protocol in English, with the spoken language during the interviews being Dutch.

General first interview question

What does quality of life mean to you as an ichthyosis patient?

Topics

Questions from this list of topics are asked in a natural way, with the participant's story leading the way. In addition, based on the previously completed questionnaire about demographics of the participant, it is considered which questions are relevant, e.g., yes/no use of medication.

Biological quality of life

How does ichthyosis affect your daily life? And what has the greatest impact?

- Physical symptoms of ichthyosis (cues: pain, itching, mobility), how limiting are these symptoms?

- Daily skin care, how limiting?
- Medication use, effectiveness, yes/no side effects, how limiting?
- Sexual health, how limiting?
- Challenges regarding a desire to have children, if so, which ones?
- What are your experiences with medical care (e.g., with dermatologists, first- and second line health care)?

Psychological quality of life

How does ichthyosis affect your mental health? How does it limit your quality of life? Or not at all?

- Self-image/self-esteem? (Cues: shame, stress, self-confidence)
- Do you have any concerns related to ichthyosis?
- Do you think about ageing with ichthyosis? In what ways? And can medical care support aging with ichthyosis, if so, how?
- How do you view the future?

Social quality of life

How does ichthyosis affect you socially?

- Does ichthyosis affect your relationships with others? (Cues: worrying about stigma, avoidance, social isolation)
- Support from family members, friends, and colleagues?
- Career and/or work situation?
- How do you perceive that society views ichthyosis?

Thank you very much for sharing your experiences with me. I have asked you all the topics that are on my list. Please indicate whether there are any relevant topics that were not discussed yet but that you would like to add to this interview.

How do you look back on this interview? Any feedback for me?