DEVELOPMENT OF THE HAEMOPHILIA AGE-GROUP SPECIFIC QUALITY OF LIFE QUESTIONNAIRE
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OBJECTIVES: To develop a haemophilia-specific questionnaire exploring Quality of Life (QoL) of four age groups: adult (18–36 years), adolescent (12–17 years), children (7–11 years) and young children (3–7 years).

METHODS: The questionnaire was developed in French following a literature review and in-depth interviews among 3 men suffering from severe haemophilia, 3 mothers of haemophilia children and 5 clinical experts (2 haematologists, 1 paediatrician, 1 nurse and 1 psychologist). RESULTS: An adult version of the questionnaire was first developed using patient’s verbatim. It contained 89 questions and covered the following 7 quality of life domains: Haemophilia and its treatment, Daily life, School, Professional life, Leisure activities and sports, Family and friends, Emotional well-being and Future perspective. Three other versions of the questionnaire were developed simultaneously based on the adult version: 77-item adolescent questionnaire, 22-item children questionnaire and 43-item parent of children questionnaire. All domains were covered in all versions, except for professional life. All age-group versions are self-administered including children from 7 to 11 years old. In addition parents fill in the 45-item questionnaire for 3–11 age groups. Content validity of the questionnaires was submitted to a Scientific committee for revision and approval. The questionnaire is currently being evaluated in a French cross-sectional pilot study including 54 severe haemophilia A patients. The objectives are to describe QoL items among different age groups, assess the acceptability and the relevance of the questionnaire and perform item-reduction. CONCLUSION: The reduced QoL questionnaire will be available to the scientific community soon for further psychometric analysis. The Haemophilia age-group QoL questionnaire offers the unique opportunity to assess haemophilia patients’ QoL from early childhood to adult life. This study was supported by a grant from Baxter.

PITUITARY GLAND DISORDERS—Quality of Life Studies

THE USE OF A CONDITION-SPECIFIC QUALITY OF LIFE MEASURE (QUALITY OF LIFE—ASSESSMENT FOR GROWTH HORMONE DEFICIENCY IN ADULTS) IN A GENERAL POPULATION
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Generic measures of health-related quality of life (HRQoL) are designed for use in a wide range of therapeutic settings whereas condition-specific measures have a much narrower focus. The performance of the latter in general population settings is largely unknown. OBJECTIVES: 1) To demonstrate the differential health status of individuals with a specific condition and hence its health burden; 2) to test the discriminatory power of a condition-specific measure of HRQoL and; 3) to develop normative reference values of QoL-AGHDA. METHODS: