AHMED A-QOL

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OBJECTIVES: Congenital diseases such as haemophilia and their treatment are influencing the every-day-life of patients and their families and impact on their health-related quality of life (HR-QoL). Haemophilia is a rare bleeding disorder in which bleeding events can occur spontaneously or after minor traumas. For the adequate assessment of HR-QoL validated instruments are necessary. In the COCHE Study (Cost of Care of Haemophilia) HR-QoL of adult haemophilia patients was assessed with a newly developed disease-specific questionnaire, which was validated in this study. METHODS: In the naturalistic, multicentric, longitudinal COCHE Study 233 adult haemophilia patients without inhibitors were enrolled from 23 Italian Haemophilia Centers. HR-QoL was assessed together with information on demographics, clinical and socio-economic outcomes. HR-QoL was assessed with generic (SF-36, EQ-5D) and disease-specific (Haem-A-QoL) instruments. Results will be presented concerning HR-QoL assessed with Haem-A-QoL. RESULTS: Psychometric characteristics of the pilot testing of Haem-A-QoL questionnaire could be confirmed in the COCHE Study. Patients showed mainly impairments in the dimensions “sport”, “future” and “physical health”. Most of them (73.6%) had to refrain ‘often’ or ‘always’ from sports like soccer, concerning their “future” 48.5% thought ‘often’ or ‘always’ that their life plans are influenced by their haemophilia. Pain in the joints was reported ‘often’ or ‘always’ by 40.2%. Differences related to socio-demographic data were found only for school level; people with a low educational level showed significantly more impairments than their families and impact on their health-related quality of life (HR-QoL) in patients who switched from on-demand treatment to prophylaxis. METHODS: A prospective, open study design was chosen. Patients receiving on demand treatment aged 18 years or more and affected by severe haemophilia A were enrolled at two Italian haemophilia care centres at the moment of their switching to prophylaxis therapy. Information related to the on-demand treatment period (ODT), six months before enrolment, and to the prophylaxis time period (PT), six months after enrolment, has been obtained at baseline and at the end of the follow-up period. Two generic HRQoL questionnaires, EuroQol (EQ-5D) and Short Form 36 (SF-36) have been used, higher score corresponding to better quality of life. RESULTS: Ten patients returned HRQoL questionnaire: the median age was 31.9 years (ranging from 23 to 58 years). At the end of the follow-up period, SF-36 showed a statistically significant improvement in patients quality of life in some domains (“Physical Functioning” and “Bodily Pain”, p < 0.05) and in the Physical Component Summary (mean score after OD 43.9 vs. 48.3 after PT, p < 0.05). Results obtained with EuroQol-5D were comparable to those showed by SF-36, with significantly different Visual Analogue Scale scores after ODT vs. after PT (67.9 and 72.9 respectively, p < 0.03). CONCLUSIONS: Prophylaxis therapy in adult patients with severe haemophilia showed to provide a significant improvement in HRQoL and it should therefore be considered in a cost utility evaluation.