

optimal health care through the elicitation of physicians' and pharmacists' preferences to health care, even in the particular context of hemophilia management.

PBR9

#### ASSESSING HEALTH-RELATED QUALITY OF LIFE IN ROMANIAN HAEMOPHILIACS

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**OBJECTIVES:** Inadequate treatment of haemophiliacs leads to high rate of chronic arthropathy, high number of transfusion-transmitted diseases and poor social integration. The objectives of our study were to measure HRQOL and utilities in haemophilia patients and to evaluate the influence of haemophilia severity, patient's age and socio-professional status on HRQOL and utilities. **METHODS:** We used SF-36 and EQ-5D questionnaires in 100 haemophilia patients with severe (66), moderate (18) and mild form (16 cases), registered and treated in Haemophilia Center Timisoara. Mean age of the patients was 23.14 years. We considered two age groups: 16–24 years (60 patients) and 25–34 years (40 patients). Seventeen of the haemophiliacs were schoolboys, 13-university students, 19-employees and 51 were handicapped with social support. **RESULTS:** Compared with Romanian general population norms (available only for SF-36 questionnaire) HRQOL is affected in haemophilia patients in both age groups, although age was not a strong predictor of HRQOL or utilities. Haemophilia severity was found to have a strong influence on HRQOL and utilities. Regarding the socio-professional status, handicapped with social support had the lowest HRQOL scores and utilities values. **CONCLUSIONS:** Our results confirm the need to develop special long-term national programs in order to improve haemophilia treatment, to reduce the number and the severity of complications, to offer a better social integration of the patients and to improve their quality of life.

PBR10

#### ESTABLISHING HEMOPHILIA PATIENTS' PREFERENCES IN PROPHYLAXIS: A CONJOINT ANALYSIS PILOT STUDY

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**OBJECTIVES:** To establish which characteristics patients consider important in prophylaxis, and if cost of treatment could influence their preferences. **METHODS:** A focus group identified five characteristics: type of product (plasma-derived vs. recombinant), infusions frequency, hemorrhages frequency, possibility to do vigorous physical activities, possibility to do usual activities. Patients gave their opinion rating each characteristic from zero (not important) to 100 (very important). Scenarios describing hypothetical treatment modalities were administered to patients who were asked to chose one for each couple presented. The characteristic "cost", expressed as increase in health care taxes, was then added in each scenario and patients were invited to make again their choices. **RESULTS:** Fifteen people, 13 adult patients and 2 parents, were enrolled. The characteristic considered most important was "usual activities" (median = 95), followed by "hemorrhages frequency" (86), "infusions frequency" (81), "type of product" (76), "vigorous physical activities" (69) and finally "cost" (50). Almost all patients did not suggest other important characteristics. Eleven patients (73%)

changed at least one choice when "cost" was present. **CONCLUSIONS:** This pilot study allowed us to identify aspects considered by hemophilia patients as important in prophylaxis. These results will help us to design a Conjoint Analysis aimed at evaluating utilities and monetary value of these aspects.

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#### QUALITY OF LIFE IS ASSOCIATED TO ORTHOPEDIC STATUS IN HEMOPHILIACS WITH INHIBITORS

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**OBJECTIVES:** We evaluated Health-Related Quality of Life (HR-QoL) in hemophilia people with inhibitors and investigated if QoL is associated to patients' clinical status. **METHODS:** The COCIS (Cost Of Care of Inhibitors) study was a longitudinal study involving 52 hemophiliacs (median age 35, 15–64) with inhibitors, 98% high responders, sequentially enrolled at 11 Italian Hemophilia Care Centers. Information on demographics, clinical status, health-care resources consumption was prospectively collected. QoL was investigated by means of the generic instruments EQ-5D and SF-36. **RESULTS:** With the EQ-profile the majority of patients reported some/moderate problems in domains "pain/discomfort" (72%), "mobility" (66%) and "usual activities" (54%). Around one third declared some/moderate problems with "anxiety/depression" (34%) and "self-care" (32%). No more than 6% of patients reported severe problems in any of the domains. The EQ-Visual Analogue Scale (VAS), measuring the global health state perception, was normally distributed, with a median value of 66 (30–95). The SF-Mental Component Summary (MCS) had a median value of 52.8 (15.5–68.1), while the SF-Physical Component Summary (PCS) had a median value of 35.2 (15.2–55.0). A strong association was found between orthopedic status and global HR-QoL (EQ-VAS, Pearson's  $r = 0.56$ ,  $p < 0.01$ ). In particular, the physical component of HR-QoL was the most influenced by the patients' orthopedic status (Physical Component Summary, Pearson's  $r = -0.359$ ,  $p < 0.01$ ). Other clinical parameters, in particular inhibitor titers and bleeding frequency, were not associated with patients' HR-QoL. **CONCLUSIONS:** Modern health care strategies aimed at treating or, better, at preventing hemophilic arthropathy should be considered to improve quality of life in inhibitor patients.

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#### CLINICAL AND SOCIO-DEMOGRAPHIC CHARACTERISTICS INFLUENCE PATIENTS' PREFERENCES TOWARDS HEMOPHILIA TREATMENT

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**OBJECTIVES:** The aim of this work is to evaluate influence of clinical and socio-demographic characteristics on the strength of preferences towards each characteristic. **METHODS:** We analyzed data originated by CONAN database from 178 patients. Patients were asked to make choices between variables of replacement therapy such as perceived viral safety, risk of inhibitor development, infusion frequency on prophylaxis, pharmaceutical dosage form, way of distribution and price. **RESULTS:** The value of each characteristic was indicated by its monetary value: the monetary value for perceived viral safety was greater for moderate (2547€) compared to severe hemo-