COST OF CARE AND QUALITY OF LIFE IN HEMOPHILIACS DEVELOPING INHIBITORS AGAINST PRODUCTS OF COAGULATION: THE COCIS STUDY

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Background and scope: Bleeding and its complications cause pain, disability and lead to a dramatic impairment of the hemophiliacs’ quality of life (QoL). Problems become extreme when hemophiliacs develop inhibitory antibodies compromising the efficacy of treatment: recent therapeutic advances are likely to have improved this situation, with a sensitive increasing of health care cost. Our objective was to estimate the economic burden and QoL of hemophiliacs with inhibitors in Italy. Methods: We conducted a longitudinal, prospective, prevalence-based, multicentre Cost Of Care Inhibitors Study (COCIS), observing hemophiliacs patients with inhibitors for 18 months. Costs were evaluated from the point of view of the Italian National Health Service (NHS). QoL was measured by the means of EQ-5D and SF-36 questionnaires. Results: 52 hemophiliacs (median age 34.8, 15 - 64) were enrolled, almost all severe and high responding inhibitors. The orthopedic functioning resulted impaired in 98% of patients. Eighty-one percent had at least one bleeding event average(0.60/patient/month). Eleven surgical procedures (6 for joint replacements), 30 hospitalizations, 712 out-patients visits and 702 physiotherapy sessions were recorded during the study period. The cost of care to the NHS was 18,000 €/month/patient, 99% due to treatment products. Recombinant activated factor VII represented 50% of total medical cost, one half of it used for surgical interventions. Patients showed an important impairment of physical health perception, while psychological QoL was comparable to that in the Italian general population (1). QoL of the COCIS patients resulted not different from that in severe hemophiliacs without inhibitors (2,3). Discussion: Hemophilia with inhibitors represents an example of a rare disease that requires high amounts of resources. Effective and expensive care of hemophilia with inhibitors provides a satisfactory quality of life.