months. RESULTS: 137 patients were enrolled (median age = 28.3 years, from 2.7 to 48.5 years, 49.6% male). At enrolment 112 (81.7%) patients had at least one thalassemia related complication (42.3% had hepatic, 58.4% endocrine, 18.2% cardiac diseases, 55.5% viral infections). Patients treated with DFO were 51.5%, 31.6% were treated with L1, 16.9% with DFO + L1. Treatment in patients taking DFO cost on average €552.88/patient/month plus €211.20 for pump and consumables; patients taking L1 cost €383.25/patient/month, patients taking DFO + L1 cost €918.41. Overall, mean direct cost was €1245.33/patient/month, with ICT representing 55.4% of costs, followed by transfusions (33.1%), hospitalizations and surgery (3.3%), laboratory and instrumental tests and medical visits (3.1%), concomitant medications (1.6%), non-medical costs (transportation, 3.4%). CONCLUSION: Transfusion and ICT account for 90% of total costs, corresponding to approximately €1000/patient/month. These results can be considered conservative because some sources of costs (e.g., nursing, home care) were not estimated, anyway we do not expect the amount of not included costs would significantly affect our results.

PHM8

INDIRECT COSTS OF BETA THALASSEMIA MAJOR: RESULTS FROM THE ITACA STUDY

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People with hematological disorders such as beta thalassemia major (TM) who regularly receive blood transfusions need iron chelation therapy (ICT) to prevent iron overload. The drugs most frequently given are deferoxamine and deferiprone. So far, little is known about the costs related to iron chelation treatment. OBJECTIVE: To receive information about indirect costs due to ICT. METHODS: The Italian-THAlassemia-Cost-Sc-Outcome-Assessment (ITHACA) is a naturalistic, multicenter, retrospective study involving patients with TM of any age, on ICT for at least 3 years, sequentially enrolled at 8 Italian Thalassemia Care Centers. Indirect costs were estimated with modified versions of the “Health and Labour Questionnaire” (HLQ). RESULTS: A total of 116 Italian TM patients completed the HLQ. Forty-one patients (52.7%) were in paid employment. 21 (34.4%) had experienced absenteeism from work due to ill health in the previous 2 weeks. The average absenteeism among patients in paid employment was 0.7 days/week. Indirect costs related to absenteeism are 27.55 euros per patient a week (based on net earnings). Fifteen patients (26.4%) of patients in paid employment) were hindered by health problems at work. Indirect costs per patient based on hours needed to catch up on tasks neglected due to health problems were 9.3 euros/week. Patients in our study received 1.24 hours of household help/week, adding up to 64.74 hours per patient a year. No differences were detected in the average between patients using deferoxamine, deferiprone or a combination of both, possibly due to the limited sample size. 21 children (or their caregivers) completed the “HLQ childrenpart” (average age 10.7). In the previous twelve weeks 18 children missed schooldays (mean = 0.64 days/week) and 6 children missed regular activities. CONCLUSIONS: TM and current treatment strategies have a high impact on patients’ productivity leading to considerable costs. Children with TM miss schooldays on a regular basis.

PHM9

THE EVALUATION OF ECONOMIES OF SCOPE IN GENETIC SCREENING BY DNA TECHNOLOGY: A MODELING STUDY

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OBJECTIVE: To assess by a modeling example under which conditions a combination of adult population genetic screening programs is cost-effective. METHODS: Based on a systematic literature review, hereditary haemochromatosis (HFE) was selected as a potentially cost-effective primary DNA screening target. A secondary condition where population screening exhibits favourable effectiveness yet unfavourable cost-effectiveness is hereditary nonpolyposis colorectal cancer (HNPCC). A decision tree for DNA screening for selected mutations in adult male Caucasians was constructed from a health care sector perspective for HFE, HNPCC, both combined and all three alternatives including first-degree relatives. Cost data from a recent HFE screening cost study in Germany were applied; HNPCC mutation prevalences were estimated based on data from the German HNPCC consortium. RESULTS: The model renders a cost-effectiveness ratio of approximately 100.000 Euro per life-year gained for the dominated HNPCC screening option, 300 EUR/LYG for HFE screening and 600 EUR/LYG for combined screening. Cost-effectiveness is most sensitive to different values for HFE penetrance and cost of genetic counselling found in the literature. Despite high incremental cost-effectiveness ratios for single HNPCC mutations added, the average cost-effectiveness ratio of the DNA test remains moderate if high test specificity is assured. Effectiveness and cost-effectiveness improve substantially if first-degree relatives are included. CONCLUSIONS: Rather than disease predisposition screening for frequent single nucleotide polymorphisms (SNPs) with low penetrance, it appears worthwhile to screen for rare mutations with high penetrance, combined with screening for HFE. Product developers in the in-vitro diagnostics industry may follow this approach to design cost-effective screening tools like DNA chips. The screening algorithm should be designed in a way to minimize the number of false-positives. Pre-test counselling should identify cases of familial cancer and ensure that negative test results are not misinterpreted as private mutations cannot be identified by a test for known HNPCC mutations.

PHM10

QUALITY OF LIFE IN PATIENTS WITH BETA THALASSEMIA MAJOR: RESULTS FROM THE ITACA STUDY

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OBJECTIVES: Patients with β-Thalassemia Major (MT) require life-long blood transfusions, which often cause iron overload that may increase patients’ morbidity and mortality. Iron Chelation Treatment (ICT), based on 8–12 hour infusions of Deferoxamine and/or Deferiprone orally administered, is aimed to reduce iron overload but can be related to low satisfaction, low compliance and potentially negative consequences on clinical effectiveness and patients’ wellbeing. Aims: to investigate on Health-Related Quality-of-Life (HRQoL) of MT patients under ICT. METHODS: The Italian-THAlassemia-Cosy-S-Outcome-Assessment (ITHACA) was a naturalistic multicentre study conducted to evaluate costs, HRQoL, compliance and treatment satisfaction in MT patients undergoing ICT.