EHDN Plenary Meeting: abstracts

significantly (the shift is greater in Italy than France). In both countries, patient and caregiver HRQoL are affected greatly and to the same extent, regardless of the instrument used. For patients, physical, mental and social HRQoL domains are all seriously affected.

Conclusions Euro-HDB is the first study to comprehensively asses the cost of illness of HD and shows that it is associated with significant costs.

J22 INTER-DISCIPLINARY CLINIC FOR HUNTINGTON'S DISEASE IN NORTH STAFFORDSHIRE, UK

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Introduction It is widely agreed that a specialist service is required to meet the complex needs of HD patients and ensure that they are not deprived from essential care on grounds related to their physical or psychiatric disabilities. Our service has been focussing on developing a holistic inter disciplinary care approach in different clinical settings.

Inter-disciplinary outpatient specialist HD clinic Professionals who are running the clinic include: Consultant Neuropsychiatrist, Occupational Therapist, Speech and Language Therapist, Palliative Care Nurse Specialist, Psychologist and a Huntington's Disease Association (HDA) representative. The waiting area will have suitable refreshments; promoting appropriate eating and drinking habits. After all patients are seen, the team meet up to present individual assessments and agree a comprehensive care plan. The clinic is highly appreciated by trainees from various departments.

Service users views on our HD services The clinic is regarded as an excellent forum that fully addresses clients' and carers' needs without having to travel repeatedly for appointments (inconvenient and costly) to receive a potentially less integrated care. The appointments are conveniently arranged and the time spent in the clinic gives clinicians more insight into the family dynamics and addresses practical problems. Communication between clinicians has also improved since they are able to discuss their findings face to face and agree the way forward. On the other hand, it is acknowledged that the clinic can be rather tiring for some patients. Among other strategies, pairing up of staff or getting the patient to only see professionals that are most relevant to their difficulties, is considered. A good advance introduction to the structure of the clinic does also help clients appreciate what to expect.

Future aspirations The team have aspirations to further develop quantifiable outcomes to scientifically demonstrate the clinical and cost effective value of the service and be more able to communicate this to stakeholders.

Rehabilitation

K01

INTENSIVE MULTIDISCIPLINARY REHABILITATION FOR HUNTINGTON'S DISEASE IN ITALY: RESULTS IN A COHORT OF PATIENTS WITH CONSECUTIVE TREATMENTS OVER 5 YEARS

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Since studies on Huntington's disease (HD) mice models have shown a positive impact of environmental enrichment on the

performance of affected animals and on disease progression, research in the field of rehabilitative therapies for HD patients has been stimulated and encouraged. A pilot project on intensive multidisciplinary rehabilitation was started more than 10 years ago in Italy. This experience was the first to achieve a quantitative, as well as qualitative, assessment of the effect of rehabilitation therapy in HD patients in the short-medium term over a 2 year period. At present we are completing the data collection of 10 years of rehabilitation experience (from 2000 to 2009) involving about 100 patients, Shoulson stage I-III, with no current severe psychiatric comorbidity or advanced dementia, who underwent a minimum of 1 up to 24 consecutive treatments. The treatment programme included physiotherapy, occupational therapy, cognitive rehabilitation, respiratory exercises and speech therapy. The treatment was timed on 3 weeks of inpatient intensive treatment to be repeated up to three times a year. A standard clinical assessment was performed at the beginning of each admission using: Zung Scale (depression), Mini-Mental State Examination (cognition), Barthel Index (ADL). Tinetti Scale (balance and gait) and Physical Performance Test-PPT (performance on specific tasks) were used to asses motor and functional performance at the beginning and end of each admission. First exploration of outcomes in groups with 1 (n=85), 1-2 (n=68), ..., 1-13 (n=12) treatments showed that each 3 week period of intensive rehabilitation treatment had highly positive short term effects on the Tinetti Scale and PPT (p<0.001). A decrease in performance was very small and became significant only after a 2 year period (n=35). Treatment effect was on average 3.6 and 3.9for Tinetti and PPT, respectively, while the decrease from two

consecutive admissions (means 5.95 months after) was on average 0.2 and 0.5. This decline seems inferior to normal decline, suggesting a positive effect of the treatment effect. This is confirmed by the Barthel Index which showed a decrease of 2.2/year. Cognition capacity remained stable over the 5 year period while for depression scores a moderately decrease was apparent.

K02 USEFULNESS OF THE UNIFIED HUNTINGTON'S DISEASE RATING SCALES AND SCORES IN THE REHABILITATION OF PATIENTS WITH HUNTINGTON'S DISEASE

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Background With the complexity of symptoms of Huntington's disease (HD), its neurological and mental impairments, it is quite difficult to measure the effects of rehabilitative treatment. As part of our day care rehabilitation programme, we have pursued the question of whether the motor and cognitive scales of the Unified Huntington's Disease Rating Scale (UHDRS) and other scales used in the REGISTRY Study can be used to detect the effects of rehabilitation of HD patients.

Methods and patients By April 2010, 23 HD patients (10 women, 13 men) completed the rehabilitation programme. In one patient the final evaluation could not be performed due to organisational reasons, and one patient died of pneumonia before the end of rehabilitation (she also suffered from kidney and heart failure). At the beginning and on completion of rehabilitation, Huntington's patients are examined with the tests of the REGISTRY study. To capture mood changes, we used the Beck Depression Inventory and Hamilton Depression Scale, the competence in daily living was scored with TFC, Function Score and Independence Scale.

Results The basic data are presented in table 1 and the changes after rehabilitation in table 2. We were able to show positive effects on motor function and cognitive performance; there was a tendency to improved mood in the self-report questionnaire BDI. No treatment benefit could be achieved when the mood of the