

Improving healthcare service delivery in patients with Huntington's disease

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Background and rationale

Patients with Huntington's Disease (HD) gradually develop complex disabilities, which include somatic problems as loss of weight and sleep disturbances, movement disorder (involuntary movements, chorea, dystonia etc.), psychiatric disorders/symptoms and cognitive impairment, eventually leading to dementia. HD is a genetic disease, which is autosomal dominant hereditary. During the course of the disease, patients need increasingly more assistance and during the later stages need day to day care, often in a health care facility. However, there is a lack of knowledge on the characteristics of the Norwegian HD population, the health care services they receive as well as how we may improve the disease management and health care and behavioural problems in this group of patients.

Purpose of the project

- To identify healthcare services utilization and healthcare needs among patients with Huntington's disease
- To identify the needs among health professionals who care for patients with Huntington's disease
- To develop and evaluate an intervention aimed at healthcare professionals, and targeting behavioural problems in patients with mid- to-late Huntington's disease

Design/Methods

The project contains three sub-studies conducted in Health care region south-east of Norway. *First sub-study* is a cross-sectional survey aimed to identify the current population of patients with HD and to assess their use and needs of health care services. *Second sub-study* is a qualitative study in order to detect the most urgent difficulties and needs of health care personnel (and caregivers) with focus on patients in mid to late stage of HD and specifically their behavioural problems (i.e. apathy, irritability / aggression, obsessive / preservative behaviour). *Third sub-study* will be based on results of the first and second sub-studies and together with available knowledge (A'Campo, 2011) and experience, a feasible intervention aimed primarily at health care personnel will be developed. The intervention will focus on education, training in management of identified main problems and on improving self-perceived competency of management.

Assessment instruments and outcome measures

- Unified Huntington's disease rating scale '99 (<http://www.huntington-study-group.org/Resources/UHDRS/tabid/67/Default.aspx>)
- Modified Client Service Receipt Inventory (<http://currents.plos.org/hd/article/utilisation-of-healthcare-and-associated-services-in-huntingtons-disease-a-data-mining-study-2/>)
- The Needs & Provision Complexity Scale (NPCS) for Long-Term Neurological Conditions (LTNC) (<http://www.csi.kcl.ac.uk/npcs.html>)
- EQ-5D Questionnaire (<http://www.euroqol.org/>)

Status per 30.06.2014

- 85 patients included in the first sub-study
- Data base is created
- Preliminary statistical analyses are underway

Publications

- Poster presented at the European Conference for Rare Diseases (ECRD) 2014, May 8-10th
- Two posters accepted for presentation at the European Huntington's Disease Network (EHDN) 2014 conference, September 19-11th