

Euthanasia and physician assisted suicide in Huntington's disease, an investigation amongst patients and physicians.

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To investigate the opinion of physicians about euthanasia and/or physician assisted suicide in HD patients, in The Netherlands and surrounding European countries. To investigate the opinion of patients about euthanasia and/or physician assisted suicide...

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Movement disorders (incl parkinsonism)
Study type	Observational non invasive

Summary

ID

NL-OMON36108

Source

ToetsingOnline

Brief title

Euthanasia in Huntington's Disease

Condition

- Movement disorders (incl parkinsonism)

Synonym

chorea of Huntington, Huntington's disease

Research involving

Human

Sponsors and support

Primary sponsor: Leids Universitair Medisch Centrum

Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: Advance directives, Euthanasia, Huntington's disease, Physician assisted suicide

Outcome measures

Primary outcome

Evaluation of thoughts about and use of euthanasia or physician assisted suicide in The Netherlands and surrounding European countries with physicians.

Evaluation of thoughts about and use of euthanasia or physician assisted suicide in The Netherlands and surrounding European countries with patients

Secondary outcome

When investigating this subject, we must consider the law. Are there any legal rules on the subject to which a physician must comply? Can we see a change in attitude among politicians and changes in the law regarding the subject of euthanasia?

Study description

Background summary

Over the last few years the number of requests for euthanasia in patients with Huntington's Disease (HD) is increasing. With a changing attitude from society and families towards euthanasie this has become an actual issue for patients and their physicians. Extensive research has been done on the subject of euthanasia in patients with for example ALS but not in patients with HD.

Study objective

To investigate the opinion of physicians about euthanasia and/or physician assisted suicide in HD patients, in The Netherlands and surrounding European countries.

To investigate the opinion of patients about euthanasia and/or physician

assisted suicide in HD patients, in The Netherlands and surrounding European countries.

Study design

1. semi-structured interviews with physicians (approx 15)
2. semi-structured interviews with patients (approx 15)
3. questionnaire sent to physicians (approx 200)
4. questionnaire sent to patients. (approx 300)

Study burden and risks

The burden consists of an interview and a questionnaire

Risks are possible emotional burden and emotional distress caused by the type of questions asked.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

Known gene carrier of Huntington's disease (HD), pre-manifest or manifest.
Over the age of 18.
Partner of family member of a gene carrier available
Patients have to be able to communicate, written or oral

Exclusion criteria

Decline informed consent
Gene carriers suffering from severe depression.
Patients or gene carriers who are suicidal
Patients who have an addiction to alcohol or drugs, which changes their judgement

Study design

Design

Study type: Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

Recruitment

NL
Recruitment status: Recruitment stopped

Start date (anticipated): 06-01-2012

Enrollment: 300

Type: Actual

Ethics review

Approved WMO

Date: 19-08-2011
Application type: First submission
Review commission: METC Leiden-Den Haag-Delft (Leiden)
metc-ldd@lumc.nl

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register	ID
CCMO	NL35588.058.11