Reasons for exclusion prenatale diagnosis or preimplantation genetic diagnosis in Huntington disease

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This study aims to get insight in reasons and motives of couples who choose for exclusion prenatal or preimplantation genetic testing. We will explore experiences of these couples in order to give recommendations for counseling of future couples....

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

Summary

ID

NL-OMON37329

Source
ToetsingOnline

Brief title
Reasons for exclusion PND or -PGD

Condition

- Movement disorders (incl parkinsonism)

Synonym
Huntington disease

Research involving
Human

Sponsors and support

Primary sponsor: Medisch Universitair Ziekenhuis Maastricht
Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: exclusion testing, Huntington disease, preimplantation genetic diagnosis, prenatal diagnosis

Outcome measures

Primary outcome

Motives in the decision making process for exclusion testing

Reasons why the at risk person decided not to be tested

Recommandation for future counselling

Make an inventory of the future interest for exclusion PGD

Secondary outcome

NA

Study description

Background summary

Huntington disease is a neurodegenerative disorder with autosomal dominant inheritance. Age at onset is usually at adult age. This devastating disorder has great impact on genecarriers and their familymembers, also in the presymptomatic phase.
Possible gene carriers, with 50% risk to be affected in the future, who do not want to be informed about their carrierstatus, and who want to prevent transmission of the disease to offspring, have the possibility to choose for prenatal exclusion testing or for preimplantation exclusion testing. These couples, but also health care workers and policymakers are confronted with ethical and moral dilemma's regarding exclusion testing. This study aims to explore motives for exclusion testing.

Study objective

This study aims to get insight in reasons and motives of couples who choose for exclusion prenatal or preimplantation genetic testing. We will explore experiences of these couples in order to give recommendations for counseling of future couples.
Futhermore, we will explore the choices the couples made and how they finally

fullfilled their childwish. Also, we will ask the couples for the reason why they did not want te be tested in the past.

Study design

This is a retrospective cohort study of couples who underwent exclusion prenatal testing or exclusion PGD. They will be asked to participate in a semistructure interview (lasting one hour) concerning their reasons to choose for this type of testing.

Study burden and risks

This study comprises one semistructured interview, lasting about one hour. Probably adverse consequences of the interview may appear when sensitive, difficult experiences are dragged up. The interviewer has a large experience with Huntington disease and we expect that she will be capable to handle these emotions. We guarantee adequate acute support and/or referral to a psychologist if necessary.

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

Couples who undewent prenatal exclusion testing.
Couples who were referred for PGD and underwent PGD treatment in Maastricht or Brussels

Exclusion criteria

Unable to give informed consent
Poor physical of psychological condition due to symptoms of Huntington disease

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Treatment

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	17-02-2012
Enrollment:	35
Type:	Actual

Ethics review

Approved WMO

Date:	12-12-2011
Application type:	First submission
Review commission:	METC academisch ziekenhuis Maastricht/Universiteit Maastricht, METC azM/UM (Maastricht)
Approved WMO Date:	24-02-2012
Application type:	Amendment
Review commission:	METC academisch ziekenhuis Maastricht/Universiteit Maastricht, METC azM/UM (Maastricht)

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	NL38536.068.11