The Gilles de la Tourette follow-up study: a study on the long term development of GTS.

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1) What is the long-term course of tics and comorbid OCD, ADHD and Quality of life in patients with GTS? 2) What are determinants of favourable versus unfavourable course?

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Other condition
Study type	Observational non invasive

Summary

ID

NL-OMON34954

Source
ToetsingOnline

Brief title
The Tourette follow-up study

Condition

- Other condition
- Neurological disorders congenital
- Anxiety disorders and symptoms

Synonym
tics, Tourette syndrome

Health condition

bewegingsstoornissen

Research involving
Human

Sponsors and support

Primary sponsor: Universiteit Utrecht
Source(s) of monetary or material Support: Stichting steun VCVGZ

Intervention

Keyword: follow-up study, OCD, tics, Tourette

Outcome measures

Primary outcome

Primary outcome variables will be (change in) tic diagnosis and tic severity using the Yale Global tic severity scale (YGTSS).

Secondary outcome

Secondary outcome variables are: (change in) OCD diagnosis and OC symptom severity (measured with the YBOCS), (change in) ADHD diagnosis and severity (measured with the CAARS), and (change in) Quality of Life measured with the QOL. Information obtained through the partners will be used in the analyses to establish pschosoial functionning in the patients.

The following variables are used to enter in the models as predictors of outcome: baseline tics/ tic severity, baseline OC symptom severity, baseline severity of ADHD, age at onset, illness duration, sex, family history, number and severity of life events, and psychosocial status at baseline.

Neuropsychological parameters that are used in association with tic severity, and severity of comorbid OCD/ ADHD are: Stroop color-word test and Stroop interference control (cognitive inhibition), Go-no-Go task (motor inhibition),

ID/ED set shifting task.

Study description

Background summary

On the course of Gilles de la Tourettes disorder (GTS) and its comorbidities (most importantly OCD and ADHD), only small retrospecitive studies (including between 20-60 patients, in children and adolescents) have been published to date, that require replication and extension. Naturalistic studies on course in adults with GTS have not yet been carried out. Thus, little is known on specific environmental factors associated with long-term outcome of tics, comorbidities and quality of life in GTS patients.
The aim of this project is therefore to answr clinically important questions such as: What are specific provocative factors, what are the protective factors involved in long term persitence or remission of tics (and comorbid OCD and ADHD)? What is the role of gender in tic development? To what extent are tics and comorbid OCD and ADHD more persistent in adults than in children and adolescents? What is the influence treatment on the persistence or reduction of symptoms in the longer term? To what extent are socio-economic factors, life events, and comorbid disorders/traits predictors of course?
The current study will be the first larger-scale study that investigates course and predictors of outcome in GTS using dfferent age groups as a starting point.

Study objective

1) What is the long-term course of tics and comorbid OCD, ADHD and Quality of life in patients with GTS?
2) What are determinants of favourable versus unfavourable course?

Study design

This project encompasses a naturalistic follw-up study that will be carried out at the department of clinical and health psychology of Utrecht university. All patients with GTS who have visited the anxiety outpatient clinic of GGZ Buitenamstel (Amsterdam) between 2001 and 2008, either to receive treatment or counseling, or -through the GTS patient society- and who has participated in a genetic study, will be recontacted and re-invited for the follow-up study.
After written informed consent has been given, a research assistant will send self-report questionnaires to fill out.
Further, the patient is interviewed, either at the department of clinical and health psychology or in the home situation.
The questionnaires and interview include: assessment of tics and comorbidity

according to DSM-IV criteria, quantitiative measurements of symptom severity); assessment of risk and protective factors of course (a.o. life-events, demographic factors, perinatal adversity). In addition, from the partners of patients (when available) information will be requested on the patients' symptoms and psychosocial functioning.
Further, neuropsychological tests are added to the follow-up measurement, targeted at asessing the ability of (motor and cognitive) inhibition and switching.

About 80% of the follow-up measurements will be identical to the baseline measurements. New measurements added to the follow-up include: questionnaires on impulsivity and life events. Further neuropsychological testing is added.

For an overview of all tests, see appendix 1 & 2 of the protocol.

All data are entered and stored in a database after datacleaning. Subseuqntly, data are analysed using growth curve analyses with model fitting procedures in mplus.

Study burden and risks

The risks associated with participation are minimal. The time span and emotional feelings evoked by the questionnaires might cause some burden for the patient.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adolescents (12-15 years)
Adolescents (16-17 years)
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

Persons with GTS and their partners.

Exclusion criteria

Persons on whom baseline measurements are incomplete or un available.

Study design

Design

Study type: Observational non invasive

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

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	18-10-2010

Enrollment:	310
Type:	Actual

Ethics review

Approved WMO Date:	26-08-2010
Application type:	First submission
Review commission:	METC Universitair Medisch Centrum Utrecht (Utrecht)

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	NL31720.041.10