Prevalence of tics, tic-severity and quality of life in Tourette syndrome in the middle-aged and elderly: an observational study

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The prevalence of tics, tic-severity and quality of life in 50 patients with Tourette syndrome aged >50 years will be assessed.

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

Summary

ID

NL-OMON42132

Source
ToetsingOnline

Brief title
Tourette in the elderly

Condition

- Movement disorders (incl parkinsonism)

Synonym
Tourette syndrome

Research involving
Human

Sponsors and support

Primary sponsor: HagaZiekenhuis
Source(s) of monetary or material Support: maatschap neurologie hagaziekenhuis

Intervention

Keyword: Elderly, Middle-aged, Tics, Tourette syndrome

Outcome measures

Primary outcome

The primary outcome measure is the total tic severity score on the Dutch version of the Yale Global Tic Severity Scale (YGTSS). The YGTSS is a well-established, semi-structured clinician derived rating scale with satisfactory convergent and discriminant validity and interrater agreement. Information on tic severity is acquired for motor tics and vocal tics separately in five dimensions: number, frequency, intensity, complexity, and interference. These dimensions are summated and the subscale scores are obtained. A rating of impairment is added to provide a total tic severity score that ranges from 0 (no tics) to 55 (severe tics).

Secondary outcome

Secondary outcome measurements include general assessment of quality of life, severity of premonitory urges and severity of comorbidity. The presence of neuropsychiatric comorbidity will be assessed by a validated mini neuropsychiatric interview (M.I.N.I.). If ADHD is present, severity is measured with the Conners' Adult ADHD Rating Scales (CAARS). In case of comorbid OCD, the Yale Brown Obsessive Compulsive Scale is administered. Autism is measured with the Autism Spectrum Quotient. Depression will be measured using the Beck Depression Inventory Scale. Co-occurrence of migraine will be assessed using a semi-structured headache questionnaire.

Quality of life is measured using the Gilles de la Tourette Syndrome*Quality of

Life Scale. The GTS-QOL is a 27-item, patient-reported scale which measures GTS-specific health related quality of life on 4 subscales (psychological, physical, obsessional, and cognitive subscale). The GTS-QOL demonstrated satisfactory scaling assumptions and acceptability, high internal consistency high reliability and test-retest reliability, and supported validity. It takes into account the complexity of the clinical picture of GTS. Health related quality of life (HRQOL) will be assessed using the TNO-AZL questionnaire for Adult*s HRQOL (TAAQOL). This questionnaire measures health status problems weighted by the impact of problems on well-being on 12 multi-item scales: gross motor functioning, fine motor functioning, cognitive functioning, sleep, pain, social functioning, daily activities, sexuality, vitality, positive emotions, depressive emotions and aggressiveness. Higher scores indicate a better HRQOL (range 0-100). Scores will be compared with an age-matched Dutch reference group provided by TNO. Psychometric performance (reliability and validity) of the TAAQOL is satisfactory.

Study description

Background summary

Gilles de la Tourette syndrome (GTS) is a complex neuropsychiatric disorder that is characterized by tics. Tics are brief, sudden, rapid, recurrent, irresistible, non-rhythmic, stereotyped motor movements or sounds. Most frequently, tics are preceded by an unpleasant somatic phenomenon that is momentarily alleviated by performance of the tic (premonitory urge). Usually, they have a childhood onset. At the severe end of the spectrum, tics may have a strong impact on mental and physical health affecting social, educational and occupational functioning (problems in obtaining partners or friends, drop out from school, loss of work productivity). Physically, tics may lead to damage or pain due to the overstraining of muscles. GTS is associated with a wide variety

of associated behaviors and psychopathologies, including attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD) and autism. In addition, the frequency of migraine in patients with GTS is fourfold higher than in the general population.

It is well known that tics can persist into adulthood in 33-50 % of patients. Recent studies that studied the impact of Tourette syndrome in adult patients showed a decreased perceived quality of life and higher levels of self-reported depression. The mean age of patients studied in these studies was 30-35 years. One study reported on tics in middle-aged (>50 years of age) patients that presented for an initial evaluation at a clinic. This study by Jankovic et al reported that the vast majority of tics presenting during adulthood represented recurrences of childhood-onset tics. This study does not provide any prevalence numbers, since the patients studied constituted a selected group already referred to the clinic because of troublesome tics.
To our knowledge, there are no studies describing prevalence of tics, tic-severity and quality of life in middle-aged and elderly patients with Tourette syndrome.

Study objective

The prevalence of tics, tic-severity and quality of life in 50 patients with Tourette syndrome aged >50 years will be assessed.

Study design

Cross-sectional observational study in 50 patients
Single visit for interview and video shot

Study burden and risks

There are no risks in participating in this study. The burden associated with participation is a single visit to our hospital of 60 minutes.
The benefits of this study do not directly apply to participants, but to younger patients. After this study we hope we will be able to inform younger patients about the natural course of tics in Tourette syndrome at older age.

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

Fulfill DSM IV criteria for Tourette syndrome
Born before January 1965

Exclusion criteria

Diagnosis of dementia
Severe psychiatric disorders (e.g. psychosis)
Aphasia
Not able to speak and/or read Dutch language

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):	07-05-2015
Enrollment:	50
Type:	Actual

Ethics review

Approved WMO

Date:	26-09-2014
Application type:	First submission
Review commission:	METC Leiden-Den Haag-Delft (Leiden) metc-ldd@lumc.nl

Approved WMO

Date:	02-11-2015
Application type:	Amendment
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	NL49125.098.14