Selective mutism - A follow up study

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Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Anxiety disorders and symptoms
Study type	Observational non invasive

Summary

ID

NL-OMON34793

Source
ToetsingOnline

Brief title
Selective mutism - A follow up study

Condition

- Anxiety disorders and symptoms

Synonym
selective mutism - speech deficit

Research involving
Human

Sponsors and support

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

Intervention

Keyword: (neuro)psychological functioning, family history, psychopathology, selective mutism

Outcome measures

Primary outcome

The main objective of this study is to assess long-term outcome of subjects once referred to our department with SM. We expect that at follow up (min 2 years after treatment) the subjects will not fulfil criteria for SM anymore, but it might be expected based on the literature, that a subgroup still has symptoms of psychiatric disorders and/or neuropsychological deficits (such as reduced cognitive flexibility or attention problems). We will assess present functioning and possible remaining psychopathology in our sample and investigate whether different subgroups (children with bilingual backgrounds, children with or without language deficits) have different outcome.

Secondary outcome

We are interested in the experiences of the patients and their parents at hindsight and hope that we learn from their experience to improve our care. We aim to examine whether demographic factors, family factors or behavioural characterics correlate with severity of impairment and predict adult symptomatic outcome. Moreover we expect individuals once referred for treatment of SM to show (neuro)psychological or language deficits that might have played a role in the development of their fear to speak.

Also, we aim to examine whether children with selective mutism are more likely to have first or second degree family members with PDD or PDD-like characteristics and whether PDD or PDD-like characteristics (such as

(cognitive) rigidity) will be found more often at follow up in the individuals themselves. We expect to find an overlap between the conditions SM and PDD in a subgroup of our sample and we expect significant differences between these groups in symptomatology, treatment effect or long-term outcome.

Study description

Background summary

SM is a relatively rare psychiatric disorder in which a child consistently fails to speak in specific situations. Following a considerable number of single case studies, several cohort studies have been published in the last years. Despite these recent efforts, systematic evaluation of long term diagnosis and outcome in large patient samples is missing. Consequently many issues about the etiology of SM, mediating factors and prognosis remained unsolved.
In the department of child and adolescent psychiatry, UMC Utrecht, two behavioural therapists became specifically interested and experienced in the treatment of SM, resulting in a relatively large number of referrals, compared to other institutions. A sample of approximately 100 children with this relatively rare disorder has been collected. This is one of the largest samples in the world especially when it concerns samples that were used in follow-up studies.

Study objective

The goal of the present study is to describe this unique sample on the basis of dossier analysis at the time of referral and reassess all individuals for follow up.

VERPLAATST: The main objective of this study is to assess long-term outcome of subjects once referred to our department with SM.

The main questions are: what rest-pathology might be found in individuals once treated for SM and which factors might have influenced outcome? Are there subgroups within the sample reflecting different aetiologies and do different subgroups have different prognoses? Do children with SM show underlying neuropsychological deficits that might have played a role in the occurrence and persistence of their symptoms? To which extend are pervasive developmental disorders (PDD) found in our sample and is there an overlap between these conditions? Which factors or interventions were most helpful at hindsight and

what can we do to improve the care and treatment for patients with selective mutism? To answer these questions the SM sample will be reassessed with standardised instruments and validated neuropsychological measures and the follow-up data will be combined with the data collected at the time of referral.
INFORMATION ABOUT THE FAMILY, COMPONENTS OF TREATMENT, AND ANY PROBLEMS OR RELAPSE AFTER TREATMENT IS COLLECTED USING QUESTIONAIRRES FOR THE PATIENT AND HIS/HER PARENTS. IN ADDITION WE WILL FOCUS ON A GROUP OF BILINGUAL CHILDREN AND WE WANT TO INVESTIGATE WHETHER DEMOGRAPHIC FACTORS OR GENETIC VULNERABILITY IS
A PREDICTOR. WE ALSO WANT TO INVESTIGATE WHETHER CHILDREN WITH SM HAS AN FIRST OR SECOND DEGREE FAMILY MEMBER WITH ASD OR ASD-CHARACTERISTICS (SUCH AS (COGNITIVE) RIGIDITY). WE BELIEVE THAT THIS ASPECT IS NOT INVESTIGATED BY SYSTEMATIC INVESTIGATION AND WE EXPECT AN OVERLAP BETWEEN SM AND ASD.

Study design

Over the last decades, approximately 100 children with selective mutism have been referred to our department. Clinical information and some standardised data, such as CBCL and TRF scores and IQ data were collected and stored in their clinical files. The study design will be an observational retrospective cohort study. In addition to collecting information from the clinical files, missing information about behavioural characteristics or psychiatric disorders in the family, will be collected retrospectively at follow-up.
Follow-up data will be collected at least 2 years after treatment. To minimise a sampling bias, all children referred to our department will be asked to participate. However, it can be expected that a sampling bias will occur with individuals with poorer outcome more likely to refuse participation than individuals with better outcome. We hope to diminish any possible sampling bias by carefully addressing all former patients and providing all participants with good information. To minimise a measurement bias, we will use standardised measurements (preferebly with Dutch population norms if appropriate) as much as possible.
IF EX-PATIENTS PARTICIPATING IN RESEARCH THEY ARE INVITED TO COME TO OUR DEPARTMENT FOR COMPLETING QUESTIONNAIRES AND PARTICIPATING IN (NEURO)PSYCHOLOGICAL RESEARCH. IF THIS IS NOT FEASIBLE (EG IN RELATION TO AN ANXIETY DISORDER), WE TRY TO DO THE RESEARCH IN A SAFE ENVIRONMENT FOR THE PATIENT (EG HOME/SCHOOL). SOME OF OUR RESEARCH QUESTIONS WILL BE ANSWERED BY OBSERVATIONAL AND DESCRIPTIVE DIMENSIONS (EG CURRENT FUNCTIONING, THE QUALITY OF LIFE, PSYCHOPATHOLOGY AT FOLLOW UP, PSYCHOPATHOLOGY IN THE FAMILY). OTHERS WILL BE ANSWERED BY USING QUANTITATIVE MEASURES (SURVEYS, NEUROPSYCHOLOGICAL TASKS).

Study burden and risks

There are no benefits for the participants. There are also no risks associated

with any of the measures used. However, participating in a follow-up study can be a burden to some of the participants. Some participants might not want to be remembered to the treatment or difficulties in personal life. On the other hand, if individuals still experience difficulties in life, it might also help them to know that they are not the only ones, that a study is designed to investigate these problems in themselves and others and that, in case they need help, careful and professional help is available. We will offer clinical advice to any individual that requires our assistance.
The burden of participation in terms of time and effort to complete the questionnaires and neuropsychological test battery is moderate. We try however, to do anything possible to minimize this burden, for instance offering to visit them at home at a time or day that is most suitable for the participants. We try to minimise anxiety levels by inviting them together with a parent, unless they prefer otherwise. We also give participants who do not want to participate in the part of the study that requires direct contact with staff, the possibility to participate in part of the study by only filling out the questionnaires.
At the end of the study all participants will be informed about the results on INDIVIDUAL AND group level.

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)
Children (2-11 years)
Elderly (65 years and older)

Inclusion criteria

clinical DSM-IV diagnosis of selective mutism

Exclusion criteria

none

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):	08-06-2010
Enrollment:	100
Type:	Actual

Ethics review

Approved WMO Date:	09-02-2010
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	NL30667.041.09