CompAS
The effect of a high intensive training in augmentative and alternative communication on communicative possibilities in patients with Angelman Syndrome

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The aim of the study is to investigate the effect of an intensive high frequent parental coaching intervention on communicative abilities in patients with AS. Patients with AS who receive standard care, will serve as controls. Parents/caretakers in...

Ethical review	Approved WMO
Status	Pending
Health condition type	Movement disorders (incl parkinsonism)
Study type	Interventional

Summary

ID

NL-OMON50653

Source
ToetsingOnline

Brief title
CompAS

Condition

- Movement disorders (incl parkinsonism)
- Communication disorders and disturbances

Synonym
Angelman Syndrome, intellectual disabillaty

Research involving
Human

Sponsors and support

Primary sponsor: Erasmus MC, Universitair Medisch Centrum Rotterdam
Source(s) of monetary or material Support: Angelman Syndroom Foundation (ASF) Amerika;en oudervereniging Nederland (vASN)

Intervention

Keyword: Angelman Syndrome, Augmentative and alternative communication, ModelER, Receptive language input

Outcome measures

Primary outcome

- Raw score of the Communication matrix (patient, parents/caretakers);

Secondary outcome

- Number of independently used AAC symbols (patient);

- Number of used communicative functions (parents/caretakers and patient);

- Percentage of communicative turns with AAC (patient);

- C-BiLLT (patient);

- ABC (Aberrant Behavior Checklist),

- Use of ModelER techniques (parent/caretakers)

- VAS Satisfaction scale on communication and AAC (parents/caretakers)

Study description

Background summary

Children with AS have a strong will to communicate, but live in a world in which they are surrounded by a language that they will never fully master: speech. Research shows that the ModelER approach (modelling, encourage and respond/recast) is successful to increase the use of Augmentative and

Alternative Communication (AAC) in children with an intellectual disability (Sennott, Lighty, & McNaughton, 2015; Sennott & Mason, 2016). The child first has to be immersed with AAC, all day long, in all natural environments. We start talking to typically developing children on the day they are born. We presume competence; we expect that someday they will understand and use speech themselves. Children with a developmental disability such as AS, should be even more immersed with communication than typically developing children, as they need more repetition before mastery can be expected. In our study, we presume competence in children with AS. Together with parents and their children, we will create Communication Passports, which will show how the children already communicate, what their interests are and how to help them develop their skills. Parents will then be coached how to apply the ModelER approach while doing a range of activities with their child (e.g. reading a personalized book, in- and outdoor activities) to promote independent AAC use.

Study objective

The aim of the study is to investigate the effect of an intensive high frequent parental coaching intervention on communicative abilities in patients with AS. Patients with AS who receive standard care, will serve as controls. Parents/caretakers in the intervention group will be taught to use the ModelER approach in combination with the making of communication passports, activity language displays (ALD*s) and personal storybooks (PEB*s). Our goal is to teach and coach parents/caretakers in how to immerse their child with AAC in everyday activities.

Study design

The study contains two phases. In the first phase we will study the Communication Matrix in a cohort of (N=50) of children with AS with two or more completed matrices, to be able to study natural course.
In the second phase we will focus on 17 patients with AS while their parents receive a high-frequent coaching intervention. It is a block-randomized controlled study with follow up design. (ABA-Follow up) A stands for baseline measurements, B for high intensive parental coaching intervention.
The primary outcome measure (Communication Matrix) and secondary outcome measure VAS-scale, will be compared between the interventiongroup and controlgroup.

Intervention

The study is conducted through the ABA-follow-up-design. All AS patients included in the intervention group will have a communication passport made. Following structured observation and consideration of parental goals, the most optimal AAC is made for each patient as well as ALD*s (this entire process is called AAC assessment). Baseline measurements (=A) include a) Communication

Matrix (primary outcome) and b) C-BiLLT and ABC (Aberrant Behavior Checklist) and other secondary outcome measures (see paragraph 5.1.2.) This baseline is set up to assess how well parents/caretakers and children are able to use these communication means before the start of intervention. After this a parental coaching intervention based on the ModelER approach is started (=B) with parents/caretakers, after which baseline measurements are repeated. Ten months after the start of the intervention, follow-up assessment will take place (including primary and secondary outcome measures). Outcome measures will be collected online from October 2020, due to Covid- 19 pandemic.
Block-randomization takes place in a 1:2 ratio (1 intervention versus 2 in controlgroup), stratified for age.
In the controlgroup the communication matrix will be filled out at baseline and after 10 months, also the VAS-score will be asked on satisfaction on the type of AAC that is being used and of the communication in general.

Study burden and risks

Former research has repeatedly and consistently proven that receptive language skills of patients with AS outperform their expressive language skills. In multiple case studies progress is seen after AAC intervention. However, further implementation, maintenance, and development of AAC skills often fails because of difficulties parents experience with implementing the intervention in everyday situations. They need coaching of a skilled professional. In children with special needs (not AS), the ModelER approach is already proven effective and was experienced to be easy to implement by parents/caretakers. We expect that the efforts of patients and their parents/caretakers does not weigh against the advantage they can achieve by stimulating communicative functions in the most optimal way. Behavioral problems often (if not always, or at least partly) occur, maintain and worsen because of problems in the communication to and from patients with AS. With optimal use of the communicative possibilities of the patients with AS and by correct AAC implementation, there would almost certainly be decrease of behavioral problems and improve of quality of life.
During the AAC assessment, the goals and capabilities of parents and children are closely considered. Prior experience has taught us that intervention should be a direct fit to the wishes and possibilities of parents and their children. This will also lessen the burden we place on both parents and children: we follow their goals.

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

Angelman syndroom, 2 - 65 years of age

Exclusion criteria

Uncontrolled epilepsy

Study design

Design

Study type: Interventional

Intervention model:	Other
Allocation:	Randomized controlled trial
Masking:	Open (masking not used)
Control:	Active
Primary purpose:	Diagnostic

Recruitment

NL

Recruitment status:	Pending
Start date (anticipated):	05-03-2018
Enrollment:	59
Type:	Anticipated

Ethics review

Approved WMO Date:	12-04-2018
Application type:	First submission
Review commission:	METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)
Approved WMO Date:	11-12-2019
Application type:	Amendment
Review commission:	METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)
Approved WMO Date:	05-11-2020
Application type:	Amendment
Review commission:	METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)

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	NL61427.078.17