

The perception of adult females diagnosed with CAH on childhood feminising surgery.

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The perception of adult females diagnosed with CAH, who underwent genital surgery in childhood, on early feminizing surgery.

Ethical review	Approved WMO
Status	Pending
Health condition type	Endocrine disorders congenital
Study type	Observational non invasive

Summary

ID

NL-OMON57042

Source

ToetsingOnline

Brief title

Perception of females with CAH on childhood feminising surgery

Condition

- Endocrine disorders congenital
- Adrenal gland disorders

Synonym

congenital adrenal hyperplasia - CAH

Research involving

Human

Sponsors and support

Primary sponsor: Erasmus MC, Universitair Medisch Centrum Rotterdam

Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: CAH, feminising surgery, focus group, women's experiences

Outcome measures

Primary outcome

focus group discussion - interview content

Secondary outcome

none

Study description

Background summary

In congenital adrenal hyperplasia (CAH), the 21-hydroxylase enzyme is missing or present at low levels. As a consequence, the adrenal glands are unable to produce cortisol and aldosterone. All cholesterol will be metabolized into androgens. In fetuses with 46, XX karyotype, the excessive amounts of circulating androgens will lead to masculinization of the developing external genital. About 70 years ago medical treatment became available. Infants born with CAH obtained good opportunities to survive and CAH became a congenital condition for life [1-3].

In individuals with 46,XX CAH the development of the internal genital is unaffected and patients are fertile as females. Infants with 46,XX CAH therefore, are assigned and reared as females. For many years, feminizing surgery of the masculinized external genital was conducted in order to facilitate menstrual discharge and penile-vaginal intercourse and to give the genital a female appearance. As surgeons got more experienced, feminizing surgery was often conducted in infancy [1,2].

For more than 25 years, feminizing surgery in childhood is under debate. It is argued that feminizing surgery in children too young to give their informed consent is unethical and harmful; it is disrespectful to the person with CAH (your genital is not good) and harms the child's body and sexuality. Advocates (united in Organisation Intersex International;

https://en.wikipedia.org/wiki/Organisation_Intersex_International) consider feminizing surgery as genital mutilation and call for a prohibition of all elective genital surgery until the adolescent - young adult is old enough to decide herself [4,5].

In this scenario, girls with CAH have to live with a genital with an atypical appearance. Particularly for girls with born with severe genital

masculinization (Prader stages 4-5) the atypical genital may lead to difficulties in acceptance of the female gender (by the child herself, the parents or the social network) and in exploring her sexuality as a female. Proponents of early genital surgery argue that adjustment will facilitate acceptance and will enable girls to take part in all types of social activities without fear for undue curiosity, injurious remarks, harassment or isolation [4,6-9].

In several countries elective genital surgery in children is not possible anymore [4]. In The Netherlands and in Belgium advocates ask the Ministries of Health to reform the law in order to prohibit feminizing and masculinizing surgery in under-aged children.

Evaluation of elective genital surgeries in childhood in relationship to gender, sexual functioning and psychosocial wellbeing in adulthood did not reveal an obvious advantage for early or delayed surgical intervention [10-23]. This study aim to explore the perception of young adult females diagnosed with CAH, who underwent genital surgery in childhood, on the discussion described above. According to them, what are advantages and disadvantages of early feminizing surgery? What would they decide for their own daughters? For this purpose, we will organize two focus groups, one in Ghent and one in Rotterdam.

Study objective

The perception of adult females diagnosed with CAH, who underwent genital surgery in childhood, on early feminizing surgery.

Study design

Non-interventional prospective study (observational)

Study burden and risks

Single 3 hours participation in a focus group or individual interview. Minimal mental health risk.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adults (18-64 years)

Inclusion criteria

46,XX CAH

Aged 18-50

Feminising surgery in childhood

Exclusion criteria

A potential subject who is insufficient fluent in the Dutch language

Study design

Design

Study type: Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

Recruitment

NL
Recruitment status: Pending
Start date (anticipated): 01-03-2025
Enrollment: 10
Type: Anticipated

Ethics review

Approved WMO
Date: 08-10-2024
Application type: First submission
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	NL87059.078.24