

# Perceptions about sexuality, relationships and experiences of adolescents with Cystic Fibrosis, a pilot study.

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<b>Ethical review</b>	Approved WMO
<b>Status</b>	Pending
<b>Health condition type</b>	Other condition
<b>Study type</b>	Observational non invasive

## Summary

### ID

NL-OMON29835

### Source

ToetsingOnline

### Brief title

Cystic Fibrosis and sexuality

### Condition

- Other condition
- Respiratory disorders congenital

### Synonym

Cystic Fibrosis

### Health condition

ontwikkeling sexualiteit bij chronisch zieke patienten

## 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:** Cystic Fibrosis, Information, Relationships, Sexuality

## Outcome measures

### Primary outcome

The study parameters exist from three coordinating topics. The first is the influence of CF on the development of sexuality. The second topic relies on the information concerning sexuality which adults with CF have received during their youth. The third topic relies on the experiences with sexuality and relationships of CF-patiënts.

### Secondary outcome

Undefined

## Study description

### Background summary

Cystic Fibrosis is a sickness which is not as yet to heal. It is a hereditary sickness which is caused by a faulty gen, what leads to the shaping of thick, tough mucilage in the air ways. This mucilage piles up himself and hampers breathing. Moreover this mucilage promotes the beginning of chronic airwayinfections, which causes much damage to the lungs and eventually lead to death. For the live of a young CF-patiënt this means that he or she has to keep up his condition continuously and that their development of growth lags behind. Because of this, puberty frequently starts at an older age than with healthy youths. Because there is not yet enough information concerning the influence of CF on sexuality and relations of young people, it is necessary that this

will be examined more closely. An important fact with this is the fast development of forms of treatment, as a result of which CF-patients become older than before. Because of this they will also have more experience with sexuality and relations than was the case with former patients. It is therefore important for the knowledge concerning CF that the sexuality perception of young people with this sickness will be examined.

## **Study objective**

The objective of the research is to examine the perspective of adults with Cystic Fibrosis concerning sexuality and to examine which factors are of influence, so that we 1.) acquire insight in giving meanings and perception of sexuality in the adolescent and adult period at people with CF.

2.) are able to identify CF-specific problems of sexuality

3.) establish a scientific well composed follow-up study about the development of sexuality at adolescents with CF as a result of the insights which we will obtain with this pilotstudy.

4.) Can improve ambulatory manner with young people in the follow-up study on the basis of the ideas of the adults who cooperate in this preliminary analysis.

## **Study design**

Type of research

The preliminary analysis is explorative and describing. The basis is socioscientific research. No hypotheses are put.

Method

At this research only one method is used, namely the interview. The participants to the preliminary analysis will be asked to agree with an interview concerning the subjects sexuality, relationships, experiences and information. During this interview they are asked to tell their own story to us by means of a semi-structured list with subjects (topic list - see appendix). The interview takes place on a location chosen by the respondent and will last no longer than an hour. There will be a 10 euro book coupon as compensation. The interview is entirely taken on tape and will be written out afterwards by the independent research worker. The final report will be transmitted to the participants. They are asked to read it and to provide us comments where necessary. The revised report is offered to the participants for approval. The tape will be destroyed after finalizing the research and all data will be considered as confidential. Also the data will be made anonymous.

## **Study burden and risks**

## Advantages and disadvantages for the participant

There are no advantages for the participant to this research. The only disadvantage for the participant to this preliminary analysis is that it costs time. No interventions are performed and the general practitioner is thus not informed concerning this research. Instead, we have chosen to inform a welfare officer about this study so that the participant can turn to this person in case of possible questions or observations as a result of the interview.

## Risks

The interview concerns a sensitive and personal subject. It is possible that the interview rakes up memories which makes the respondent feel uncomfortable at. This is also applied to the research worker who will anticipate on the indicators which the respondent delivers, such as avoiding a question or possible silences.

Of course the interview will be stopped as soon as the participant indicates this.

## Contacts

### Public

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### Scientific

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## Trial sites

### Listed location countries

Netherlands

## Eligibility criteria

### Age

Adults (18-64 years)

Elderly (65 years and older)

### Inclusion criteria

There has been chosen for this population, because they are adults and able to make their own decisions. Given the subject it seemed our judicious to talk firstly with adults concerning feelings on sexuality. Moreover their insights in the follow-up studies can produce a more and more careful approach of adolescents.

### Exclusion criteria

Patients with Cystic Fibrosis  $\leq 20$  years fall outside the population of this research, because we would like to talk with adults as "experience experts" firstly. Furthermore we will select people on psychological strain. If they're already involved in other research projects or if they're busy with a lungtransplantation for instance, we won't approach them with this research.

## Study design

### Design

**Study type:** Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Health services research

### Recruitment

NL

Recruitment status: Pending

Start date (anticipated): 24-05-2006

Enrollment: 10

Type: Anticipated

## Ethics review

Approved WMO

Date: 05-09-2006

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	NL12740.078.06