

Join Us!

# VIBSEN BREGNBALLE DORIS THOMSEN



# CYSTIC FIBROSIS IN DENMARK



Copenhagen University Hospital



Aarhus University Hospital

# PATIENTS

- 316 CF patients
  - 104 children
  - 212 adults
- Age span 0- 66 years
- 157 CF patients
  - 75 children
  - 82 adults
- Age span 0-49 years
- 92 CF-ptt DLTX
  - 1 in 1990, still alive
  - 1 in 1994, still alive
  - 2 RE- DLTX (2011 and 2013)

Copenhagen Center

Aarhus Center



# Side effects of treatment with oral antibiotics in small children with cystic fibrosis

Karin Risager Jakobsen, Vibsen Bregnballe  
Department of Pediatrics, Aarhus University Hospital, Denmark  
karijako@rm.dk

POSTER NO. 245

## Side effects of treatment with oral antibiotics in small children with cystic fibrosis

Karin R. Jakobsen

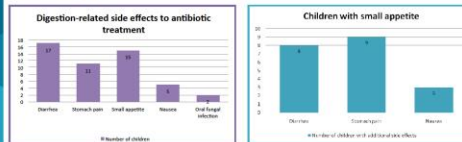
### Background and objectives

Frequent antibiotic treatment is common in patients with cystic fibrosis (CF). The aim of the study was to explore digestion-related side effects of oral antibiotics in small children with CF and the impact of probiotic treatment on these side effects.

### Material and methods

All parents of children from 0 to 5 years followed at the CF Centre at Aarhus University Hospital, were invited to participate in a questionnaire survey. Parents of 31 children accepted to participate. Areas of interest were diarrhea, stomach pain, nausea, small appetite and oral fungal infection.

### Results 1.1



74 % (N=23) of the children in antibiotic treatment had one or more digestion-related side effects

48 % (N=15) of the children in antibiotic treatment had small appetite; several of these 15 children had additional side effects

### Results 2.2

*Probiotic treatment:* Twentytwo children had diarrhea and/or stomach pain. Of those 54 % (N=12) were treated with probiotics. None reported probiotics to be effective concerning absence of diarrhea and/or stomach pain

### Conclusion

Most of the children had side effects from treatment with antibiotics, but only half of them were treated with probiotics for the side effects. Two children had oral fungal infection and were treated with oral fungicides. Probiotics was not reported to be effective but parents still gave the children probiotics. Most of the children with small appetite also had diarrhea and/or stomach pain. There is no consensus on treatment/prevention of digestion-related side effects of treatment with oral antibiotics in small children with CF.

POSTER NO. 248

# Taking sputum samples from small children with cystic fibrosis

Mette Pehn

M. Pehn  
V. Bregnballe  
Department of Paediatrics  
Aarhus University Hospital  
DENMARK  
metpeh@rn.dk

## Taking Sputum Samples from Small Children with Cystic Fibrosis:

# a Matter of Cooperation

These three short videos of children undergoing tracheal suction show challenges for children and parents and may help you to form an idea of how parents can support their child to cope with the procedure of tracheal suction.

If you watch the videos with a child who is older than the children in the videos, it is very important not to push the child (e.g. never say "look how cool he is - and he is much younger than you are!"). Only use the videos to show the child that he/she is not "the only one"! Use the videos for a talk about what it is difficult and to make the child believe it is possible to learn how to cope.

### Objectives

An important part of the disease control in Danish guidelines for care of patients with cystic fibrosis (CF) is a monthly sputum sample by tracheal suction. Coping to this unpleasant procedure in small children depends heavily on the support from parents and nurse. The objective of this study was to develop a tool to help parents and children to cope with tracheal suctioning.

### Methods

Three short videos showing how nurses perform tracheal suctioning to get a sputum sample from small children with cystic fibrosis were made. The videos were shown to and discussed with parents and children to help them identify their own challenges in coping with the procedure. The study was carried out in the outpatient clinic at the CF centre, Aarhus University Hospital.

### Results

The videos are a useful tool to convince the parents, nurses and children from the age of about four years that the child will succeed in coping with tracheal suctioning. It works as well as children find the videos useful in preparation for the procedure. Only very few children below the age of five years have not yet learned to cope.

### Emma



16 months - Cooperation between parents and nurse  
Emma is so young that it has to be her parents and the nurse who cooperate to make the procedure as easy as possible for her. As Emma is aware of what is going to happen from the very moment she gets to the consultation room, her parents have learned that the procedure has to be performed as quickly as possible. Her parents support her splendidly. They are very attentive and immediately after the procedure ready to comfort with toys and her dummy.

If the parents would not like to handle their child, it is our job to talk with them and try to help them. Often it will be "reluctant" for the parents to try a tracheal suctioning themselves.

From the age of 2-4 years, children are able to understand simple explanations about why they need tracheal suction; as soon as you experience the very first sign of this, it is a matter of taking the opportunity and begin to involve the child in the cooperation. You can start by offering simple options (e.g. do you want to sit with mum or dad today? Are you going to count to 2 or 3 today? Never expect or ask for too much, but know that the child cooperation as good as possible. Always praise and try to build up confidence; take time afterwards to allow the child to react, talk about it and do something nice.

### Jonas



4/5 years - Cooperation between child and nurse supported by parents  
For Jonas the most important thing still is to get tracheal suctioning over and done with as quickly as possible as he often loses courage as soon as he gets into the consultation room. He concentrates on breathing and visualizing and he needs support to focus to divert his anxiety. Before entering the consultation room, he has tested which nostril the nurse is going to use and is asked to plan what he is going to visualize. Jonas means gets on the backrest ready to support and hold his head and hands if necessary. The nurse is talking him through "the procedure with short orders: "Now you get mum on the backrest", then hold really tight onto the handlebars, like last time", "remember to breathe" and so on.

If the child do not manage so well, it will still be very important to praise and encourage him/her and have a talk about what was working and what we could work on for the next time.

It is crucial to "teach up" and make sure that the experience is never felt as a failure - even if the child is crying or was not able to cope as expected.

The challenge is to support and help the child until he/she has found a way to cope.

### Johan



4/5 years - Cooperation between child and nurse  
Johan has already learned how to cope with the tracheal suctioning, so it only crosses his mind the short time it takes to get it over and done with. The sound of suctioning is still a "nausea sound" and the nurse has to count to as little as possible. All the times Johan has protested and has been frustrated has caused no damage to his mind; on the contrary he is still a strong, lovely boy ready to face the challenges of life. Johan tells that he tried to think of how he could do the tracheal suctioning but nothing happened - and then suddenly he could.

### Conclusion

Small children with CF can learn to cope with the unpleasant procedure of tracheal suctioning e.g. by watching and discussing exemplary videos of the tracheal suctioning procedure.

The videos can be seen at:  
[www.cf.en.auh.dk](http://www.cf.en.auh.dk)  
or at the poster



# YOUTH GROUP CYSTIC FIBROSIS

Irma Thorsen, Signe Sønderup  
and Vibsen Bregnballe

## Purpose:

- Meeting other young people with CF
- Update on the latest research
- Repetition of CF knowledge

## Meetings:

- Twice a year
- From 3 - 6 pm: programme
- From 6 - 9 pm: cosiness in the hospital's youth café
- The young people decide the topics



# Transfer for unge med cystisk fibrose til voksenafsnit - Erfaringer fra CF-Center København



Transfer of adolescents from dept. For children- to dept. for adult

Rie S. Dalager  
Doris Thomsen

CF-Center København, Rigshospitalet:  
Sygeplejerske og Ungeambassadør Rie Sahlholdt Dalager, e-mail: rsd@rh.dk  
Sygeplejerske og Ungeambassadør, CF-kordinator Doris Thomsen, e-mail: Doris.thomsen@regionh.dk

**Baggrund**

CF-centeret København har ca. 40 unge patienter.

Efter etablering af et voksen CF-center i april 2011 er der opstået behov for ekstra fokus på transfer (overgang) fra børne- til voksenafsnit når patienten bliver 18 år. Erfaringer (1-3) viser, at det er vigtigt at inddrage de forskellige interessenter.

**Formål**

- At afdække behov, bekymringer, forventninger og viden blandt patienter, forældre/ omsorgspersoner og de sundhedsprofessionelle i relation til overgangen.
- Ud fra den indsamlede viden at tilrettelægge et transferprogram.

**Metode**

- Interview af:
  - 6 patienter i alderen 12-18 år
  - 2 forældre
  - 4 sundhedsprofessionelle.

Interview om:

- Behov, bekymringer og forventninger til overgangen til voksen-afsnittet samt deres erfaringer og ændringsforslag.

**Resultater**

De unge CF patienter har mange spørgsmål og bekymringer for overgangen til voksenafsnittet. Blandt andet at:

- Personalet ikke kender dem, og de har brug for viden og information om voksen-afsnittet.
- Forældrene er bekymrede for kryds-infektion på voksenafsnittet.
- De sundhedsprofessionelle har forskellige opfattelser af overgangen. Personalet på børneambulatoriet er mere bekymret for hvorledes overgangen skal foregå end voksenafsnittets personale.



Transfer



**Konklusion**

Når unge patienter overgår til voksenafsnittet, er der behov for opmærksomhed for at imødegå deres behov og forventninger. Et veltilrettelagt transferprogram er en stor hjælp i forbindelse med den overgang, der skal foregå.

References:  
1) Russell M Vine: Transition of care from paediatric to adult services, 2008. London  
2) McDonagh: Transition from paediatric to adult care services, 2009.  
3) Susan Madge: A model for transition from pediatric to adult care in cystic fibrosis, 2002

# 2014: ANNUAL REVIEW

- ⦿ - with CF- physician
  - ⦿ Status ---- and planning for next year
  
- ⦿ - with CF- contact-nurse
  - ⦿ From the current life situation - offering support for coping with cystic fibrosis (psychosocial talk)



# ANNUAL PSYCHOSOCIAL TALK

## ◎ Background (interview)

- Especially adolescents need a contact-nurse
- They find it difficult to have an open dialogue about their life situation with different nurses
- Nurses should be interested in patients existential needs (not only medication)
- Important that adolescents learn to take responsibility for their own life

# ANNUAL PSYCHOSOCIAL TALK

## **Systematic structured talk:**

- Starting with "non-dangerous" topics.  
Home, education, eating, activities, drugs...  
adherence
- Focusing on  
ressources/strengths/dreams - not  
only on problems
- Helping patients being realistic about  
everyday life having CF.
- Supporting patients in taking  
responsibility for their own treatment

**Goul:** Better adherence to treatment/showing up

# DIALOGUE

- ◉ HOME: **hjemlige forhold (socialbaggrund, livsstil)**
- ◉ EDUCATION: **uddannelse og erhvervsarbejde (socialbaggrund, livsstil)**
- ◉ EATING: **spisevaner og kropsoptagelse (ernæring, psykosocialt)**
- ◉ ACTIVITIES: **fritid, sport, venner (fester) (aktivitet livsstil)**
- ◉ DRUGS: **tobak, alkohol, (livsstil, psykosocialt)**
- ◉ DEPRESSION: **humør, selvskadende adfærd, selvmord ( psykosocialt)**
- ◉ SEXUALITY: **kærester, seksualitet, prævention, donorbørn (seksualitet/reproduktion,)**
- ◉ SAFETY: **Sikkerhed (samvær andre CF), mobning, vold (aktivitet, psykosocialt)**
  
- ◉ ADHERENCE: **medicin, viden om sygdom, self-care, (viden/udvikling)**
- ◉ FORÆLDRE/ÆGTEFÆLLE/BØRN: **(social baggrund)**
- ◉ **Hvad fungerer for dig lige nu: hvad gør dig glad**
- ◉ **Hvad ønsker du selv at tale om:**
- ◉ **KONKLUSION : aftaler, plan til næste konsultation: om (1/2) eller 1 år**

**SIGN:**



# CHALLENGES FOR CF NURSING

In CPH The Cystic Fibrosis department has just become part of Infectious disease department

- 10 beds for CF - 20 beds for Infec.
- Acute - chronic patients together
  - Nurses occupied with acute infec. patients/ means lack of time caring for the chronic CF-patients, who need educational support
  - In organizational decisions: CF group are minority
  - Many different physicians not specially focused on CF (CF patients wants continuity, e.g. skilled CF-doctor who knows them and the course of their disease)

How do we care for the CF care ?