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

POSTER NO. 245

Side effects of treatment with oral antibiotics in small children with cysticc fibrosis

Karin R. Jakobsen

POSTER NO. 248

Taking sputum samples from small children with cystic fibrosis

Mette Pehn

YOUTH GROUP CYSTIC FIBROSIS

Irma Thorsen, Signe Sønderup and Vibsen Bregnballe

Purpose:

- Meeting other young people with CF
- Update on the latest research
- Repetion 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

Brush-up in CF

Eating, talking and having fun

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

Rie S. Dalager
Doris Thomsen

Rigshospitalet

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

CF-Center København, Rigshospitalet:
Sygeplejerske og Ungeambassadør Rie Sahlholdt Dalager, e-mail: rsd@rh.dk
Sygeplejerske og Ungeambassadør, CF-koordinator 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

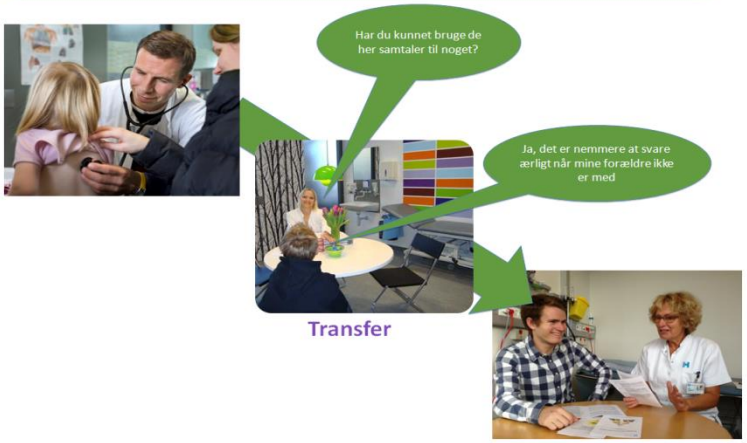
- Interview af:
  - 6 patienter i alderen 12-18 år
  - 2 forældre
  - 4 sundhedsprofessionelle.

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.



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 Viner: 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 PSYCHOSOCAIL 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 kropsopfattelse (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 (½) 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 ?