



Home treatment with intravenous antibiotics for cystic fibrosis – patients experiences

Preliminary qualitative results

INSG-CF Annual Meeting 2014 Gothenburg

A Scandinavian Nurse Specialist Group-Cystic Fibrosis study

- Aarhus, Copenhagen, Lund, Gothenburg, Stockholm, Uppsala and Oslo

Study sites

- CF centres
 - Denmark – completed
 - Sweden – completed
 - Norway – delayed start
 - Re-assessment to ethical committee for an anonymous study

Study design

- A survey with questionnaires made for three patients groups
- Language translation to
 - Danish, Swedish, Norwegian
- Respondents
 - CF patients 0-11 years – parents with child
 - CF patients 12-18 years - with parents
 - CF patients adults

Survey questions

- Focus for questions
 - Education/re-education
 - Accomplish (conducting)
 - Support and monitoring
 - Impact on everyday life
 - The overwhelming disease
- In total 25 (26) questions

Education / re-education

- Most respondents satisfied with practical instruction with infusions
 - Comments of heavy responsibility, and nobody to share with (parents)
 - Young adults demand for education, not a re-education
 - An adult "expert" also have a need for re-education
 - Change of physical reactions
 - A long life with iv...

Accomplish (conducting)

- Lack of practical and theoretical information
 - A lot of planning and organisation
 - No information of symptoms and treatment of anafylactic shock
 - Differences in information
 - Ongoing contact with CF nurse
- Better with hometreatment
 - compared to hospital treatment

Support and monitoring

- When ready to go home with this new treatment?
- The doctor is missing
- A feeling of left alone

Impact of everyday life

- Limited participation at daycare and school
 - No sport, no play, no swimming
 - Lack of time in school and missing education
 - Organisation of practical issues for giving the infusion

The overwhelming disease

- The disease is catching up
 - A feeling of being abandoned
 - Anxiety, fear, vulnerable, depressed, powerless
 - Concerned about the future
 - Tired of many years with CF
 - *"You can all go to hell!"*
- *"What to do when my old mother won't be there to insert my Butterfly?"*

Conclusion

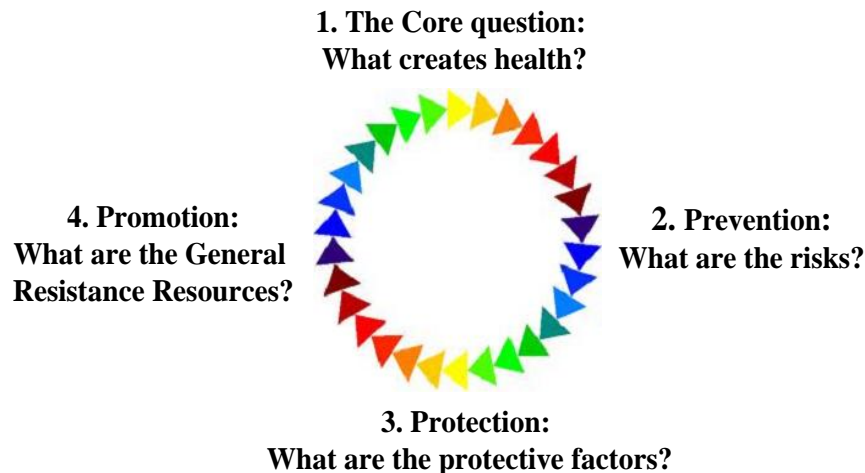
- Even all difficulties and the impact of daily life for the patient and their family, "iv. home-treatment" seems to be a good possibility to be offered.
- But, we must not forget to listen carefully if there is need for a stay in the hospital for iv. treatment.

Clinical improvement

- For best follow up with intravenous antibiotics, a closer collaboration between responsible CF physician/nurse and the CF patient while under home treatment may reduce treatment burden in the long run.

Hunting for health

A Salutogenetic research model for exploration of health



Adapted fig. from "The Hitchhikers' Guide to Salutogenesis"
Bengt Lindström & Monica Eriksson, 2010

Sence of coherence (Antonovsky)

1. The stimuli from one's internal and external environments in the course of living are **structured, predictable, and explicable**;
2. The resources are available to one to meet the demands posed by these stimuli; and
3. These demands are challenges, worthy of investment and engagement.