Determinants of parental knowledge on congenital heart disease

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13th Biennial Congress of the ESHMS
Results from the project

„Distress of parents of children with congenital heart disease“

Funded by the Deutsche Forschungsgemeinschaft (DFG)

(Az. GE 1167/5-1 und WE 2670/3-1)
Why is it important to talk about parental knowledge?

Parents have to give informed consent on the realization of a treatment

During inpatient visit care by medical staff

After discharge parents responsible for daily management of the disease
  responsible for the child’s well-being/ life
What will be presented?

What do parents of children with congenital heart disease know about their child’s illness?

Where do they lack knowledge?

Which determinants for parental knowledge can be found?
Who was interviewed?
Parents accompanying their children (< 2 years) to an inpatient visit for surgery or interventional catheterization since April 2008

When were the interviews conducted?
Latest 2 weeks after treatment
Mostly in the second week after surgery (mean value 7 days)
Study population

174 children visited Hannover Medical School for surgery or interventional catheterization

33 had to be excluded (genetic syndromes, comorbidities, …)
16 mothers refused to participate (11%)
2 children died before the interview (1%)

Study population: 143 parents
Comparison between participants and non-participants

With regard to

Parental age
Parental educational status
Severity of the heart disease
Sex of the child

No significant differences between participants and non-participants were found.
Methods

KNOWLEDGE-QUESTIONNAIRE

„Hannover Inventory of Parental Knowledge of Congenital Heart Disease“ (HIPK-CHD)

Based on the „Leuven knowledge questionnaire for congenital heart disease“

Adapted to focus on parents instead of patients
„Hannover Inventory of Parental Knowledge of CHD“

Consists of following dimensions

- General knowledge (8 items)
- Signs/symptoms before surgery (10 items)
- Signs/ symptoms after surgery (13 items)
- Individual heart disease (3 items)
- Management at home (7 items)
- Surveillance of deterioration (4 items)
- Endocarditis (20 items)
- Physical activity (6 items)
Other questionnaires used

Usage of health facilities and psycho-social factors
  *self-administered*

Parental burdens
  *Familien-Belastungsfragebogen*

Child’s developmental status
  *Bayley Scales of Infant Development II*

Demographics
RESULTS
Population’s characteristics
Parents
What do parents of children with congenital heart disease know about their child‘s illness?

Where do they lack knowledge?

Which determinants for parental knowledge can be found?
Percentage of correct answers by dimension
Socio-economic determinants influence parental knowledge on all eight domains.

Domain 'endocarditis' only determined by paternal characteristics, no maternal

No effects

Objective severity of heart disease
Subjective severity of the disease
Self assessment about understanding of information
Conclusions
Socio-economic factors represent the main influence.

If parents had the opportunity to take their child home after birth, they show a higher level of knowledge than parents whose child has to undergo surgery in an early stage of life.

Assumption: They have more time to gain information on the heart disease.

BUT

Findings show that the older the child is at time of surgery the less the parents knew about the child’s heart disease.
Prospect

Follow-up after 1 year

Brochure basing on the questionnaire and the findings
Thank you for your attention

www.mh-hannover.de/angeborene_herzfehler.html