



Nurses take over!

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Outpatient nephrotic syndrome consultation

- What was missing?
- What did we do?
- Future goals



What was missing in our way of working?

- A fixed time in our outpatient clinic
- Parents had a difficulty contacting us
- Useful information for patients in a written booklet



What did we do?

- We held a baseline survey before we started involving the nurse consultant in the outpatient clinic
- Repeated the same survey after one year
- All patients received an information letter on their first visit, regarding the new organization of our care
- The nursing consultants got a more prominent role at the outpatient clinic
- Literature search was performed, but revealed only scarce data on this subject
- We collected all scattered information and transformed it into one booklet

Our survey

- All parents and kids age 8-18 were interviewed
- Surveys were handed out if possible, otherwise sent by mail
- The baseline survey (2016) was returned by 32 parents and 25 kids.
After one year we received surveys of 36 parents and 33 kids



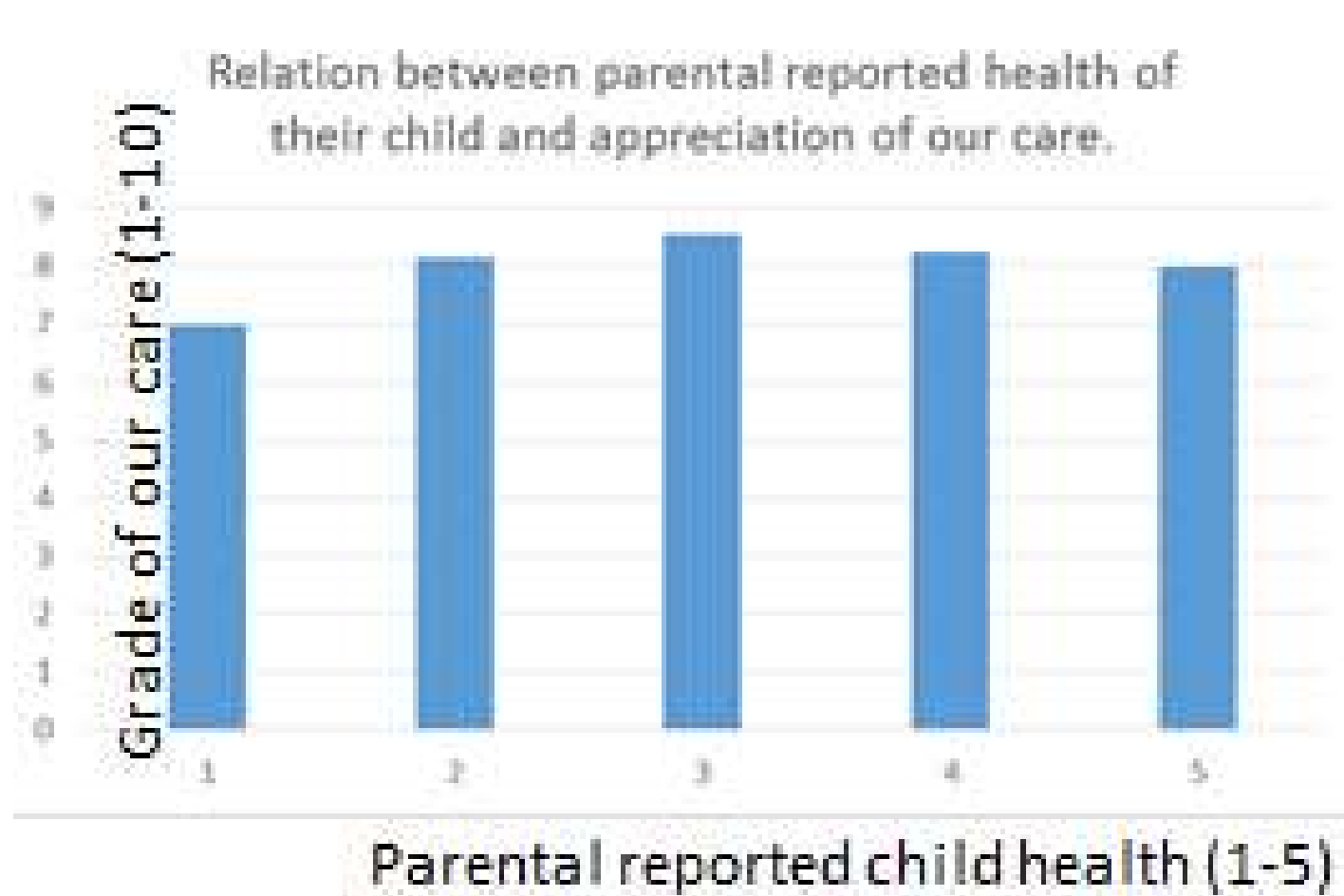
Results

- We categorised the questions into different subjects
 - Reception at the outpatient clinic
 - Care by the physician
 - Care by the nursing consultant
 - Aftercare
 - The kids surveys had additional questions for 12 years and older

Summary

Respons of parents	start	1 year
Number of returned questionnaires	32	36
Grade of our care (1-10)	8,45	8,29
Parental reported health of their child (1-5)	3,23	3,33
Female (%)	81	83
Parents of Dutch background (%)	66	53
Child age (0-6), (6-12), (12-18) year	20, 43, 43	17, 37, 46
Patients seen by the specialized nurse (%)	44	94

Response of children	start	1 year
Number of returned questionnaires	25	33
Grade of our care (1-10)	8,18	8,32
Self reported health (1-4)	2,64	2,97
Female (%)	29	39
Age (years)	12,2	12,3



Reception outpatient clinic.

- Parents tell us that is much easier to get answers to their questions by e-mail or telephone
- Waiting time is improved, the waiting time < 30 minutes is reduced. Because the nurse consultant is participating in the outpatient clinic, the number of patients for the doctor become less
- The children, specially the adolescents say that the hospital is to much adjusted, decorated for the smaller children. But the children generally are satisfied

Care by the physician

- Overall the quality of the physicians care is rewarded as good
- There is no difference between the children and the parents
- Parents rated the care on a scale from 1-5 with a 3,8
- Children rated the care on a scale from 1-5 with a 4,2
- There is no significant difference between the two measurements

Care by the nurse consultant

- Before 2016 many of the children with Nephrotic Syndrome did not see one of our specialised nurses. We participate now in the counseling of those children, and parents no how to reach us
- Some of the parents have to get used to see the nurse instead of the doctor, but they where satisfied after the consultation
- There are fewer children who have contact with the nurse themselves, most contacts are run by the parents

Aftercare

- Improved significantly compared to the baseline measurement.
Especially:
- Medication; side-effects, instruction and how to use it. The parents surveys showed a higher score than the children.
- Clarity on who and when to contact with questions has improved.



Children 12 years and older

- We asked them if they would like to come in first, without parents, and if they needed extra guidance before turning 18 years old



- What do you think they answered???

NO

“Our” nephrotic syndrome booklet

- There is lots of information to find, but it is not specific for children
- The information is not conclusive
- Information at the internet: Google into panic!
- We collected everything we already used and bundled it. This way the information provided is generic for everyone
- The parents or child can use it as a reference guide

Future

- Transition to adult centre
- Web-based questionnaire (Klik) to measure and improve QAL
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