

ALL and Down Syndrome:

Challenges in interactions and interpretation of symptoms and side-effects

Copenhagen University Hospital Rigshospitalet, Denmark
The Nordic Society of Pediatric Haematology and Oncology 

Cathrine Bohnstedt, Linn Olersbacken,
Hanne Bækgaard, Kjeld Schmiegelow,
Margareta Stenmarker, Helena Hansson
Contact: helena.hansson@regionh.dk

PURPOSE

- What is the background for the lower treatment intensity of maintenance treatment in patients with Down syndrome and ALL?
- We explored the experiences of parents of patients with Down syndrome and ALL

*Well, I like to say, the biggest effect in the first year, overall, has to be that she did not speak for almost a year.
(Mother)*

METHODS

- 14 parents to 10 DS-ALL patients treated on NOPHO ALL2008 treatment protocol from Sweden (n=7) and Denmark (n=3)
- The parents were interviewed together or alone, with or without the child and siblings, and in the family's home or by phone according to parents' wishes
- The interview-guide was structured with the topics: side-effects, treatment adherence and cooperation with the physician
- The transcribed text was analysed using qualitative content analysis

FINDINGS

Two main themes emerged in our final analysis:

- 1) Challenges in interaction and interpretation of a child with DS and ALL
- 2) Great diversity in knowledge on DS-ALL, dose regulation and side-effects during maintenance therapy

Only the first main theme is described in this abstract.

Three sub-themes were identified:

- Mental preparation of children with DS facilitates cooperation and decreases stress
- Coping behavior reflecting Down syndrome
- Interpreting symptoms is challenging

*I think it has been a problem.
She has not been able to express where the pain is or how she is doing. We have no idea, so we have been assuming things all along. (Father)*

We are able to understand him a little, little bit. It is not possible for the medical staff to ask him and get an answer. (Mother)

CONCLUSION

Parents of DS-ALL patients may experience a great challenge in the communication, interaction and interpretation of their child's symptoms and side-effects.

The thing is you can't really explain it to him (before surgery) that we had to wash him. Several times he refused, it became way too much. A long time passed before he could have a bath again. (Mother)

PERSPECTIVES

It is important to provide maintenance treatment and care with consideration for the children's extensive need for:

- adjusted care to their cognitive impairment
- the needs of a familiar environment, routines and mental preparation
- reliance on their parent as spokesperson