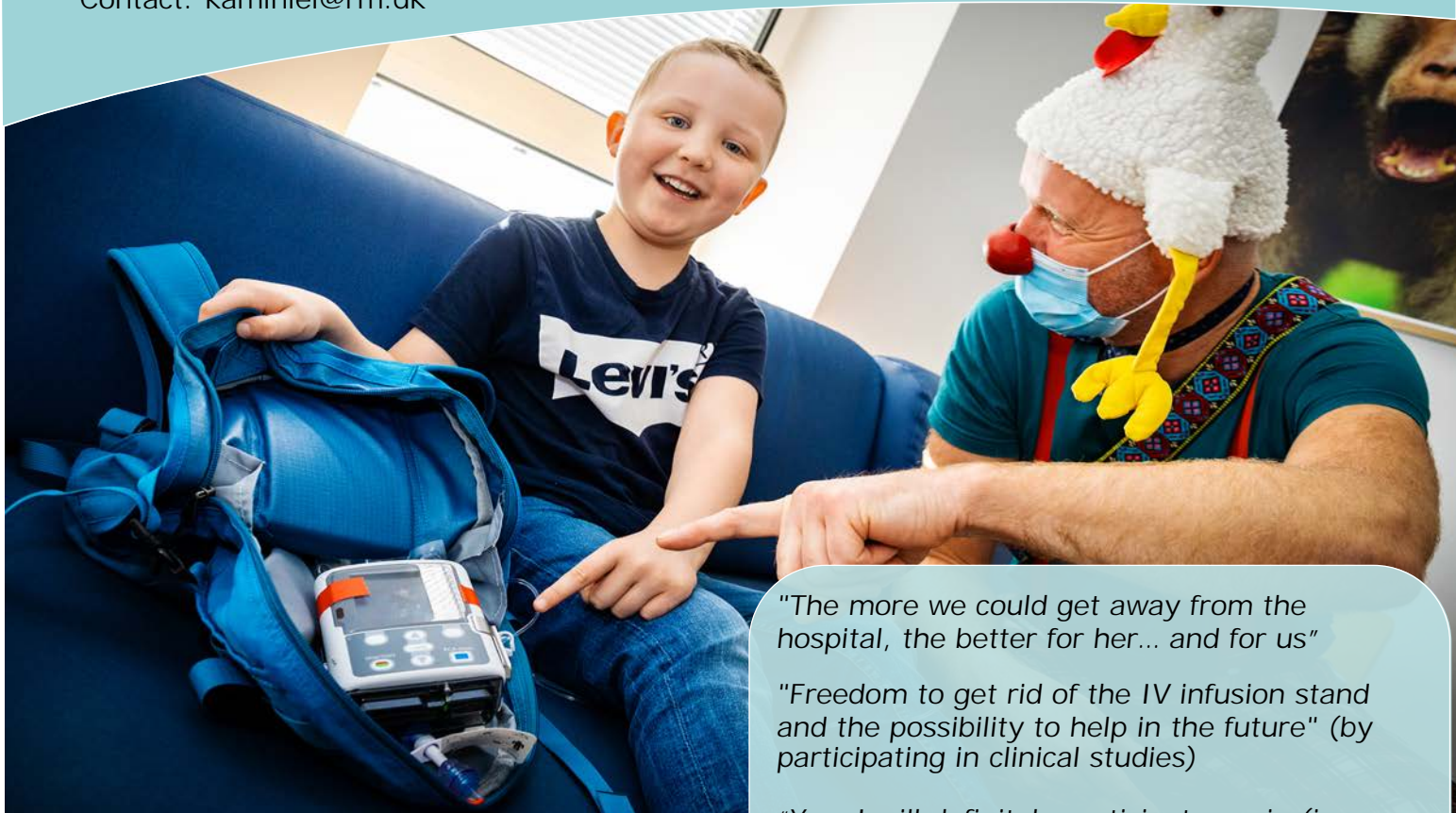


Participation in clinical studies leads to improved quality of life; experiences of parents, children and adolescents

Tofting-Olesen, Kamilla, Department of Paediatrics and Adolescent Medicine, Aarhus University Hospital
Contact: kaminiel@rm.dk



"The more we could get away from the hospital, the better for her... and for us"

"Freedom to get rid of the IV infusion stand and the possibility to help in the future" (by participating in clinical studies)

"Yes, I will definitely participate again (in clinical studies) – you don't feel being admitted to hospital"

"The possibility to go home; that gives us freedom"

Introduction

Besides immediate health benefits, other factors are important when parents consent for their underaged children to participate in a clinical study.

A possible association has been reported between patient and family experiences during participation in clinical studies and dropout rates, willingness to re-enter or enter new clinical studies, and overall quality of life.

Aims

To gain insight into the experiences of families participating in a clinical study, and clarify patient benefits, motivational or discouraging factors related to participation.

Methods

- A qualitative method was applied.
- Observations of experiences from parents, children and adolescents were made throughout a clinical study of continuous infusion of antibiotics in 38 febrile (68 fever episodes) children with cancer at Aarhus University Hospital.
- Informal patient/parent conversations in clinical situations related to start-up, during the course of and at the end of antibiotic treatment were used followed by semi-structured interviews.
- Interview data were analysed using thematic analysis.

Conclusion

- Parents described participation in this clinical study as a positive experience.
- Main themes included improved quality of life for the sick child/adolescent and the family due to increased sense of freedom and less time spent at the hospital.

Results

The 6 semi-structured interviews and 32 informal patient/parent-conversations revealed certain motivational factors for participation in and re-entering clinical studies:

- Increased freedom
- Less hospitalisation
- Increased time spent at home.

The motivational factors are illustrated by the statements above.

