

The Swedish Infant High-grade Reflux Trial – and a Focus group study of parents' experiences

Akademisk avhandling

Som för avläggande av Medicine doktorexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentlig försvaras i Tallen, Rondvägen 10, Drottning Silvias Barn- och ungdomssjukhus, SU/Östra, den 12 december 2019, klockan 13:00

av **Josefin Nordenström**

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Avhandlingen baseras på följande delarbeten:

I. J Nordenström, G Holmdahl, P Brandström, R Sixt, E Stokland, U Sillén, S Sjöström (2017)

The Swedish Infant High-grade Reflux Trial: Study presentation and Vesicoureteral reflux outcome.

Journal of Pediatric Urology, 13, 130-138

II. J Nordenström, U Sillén, G Holmdahl, T Linnér, E Stokland, S Sjöström (2017)

The Swedish Infant High-grade Reflux Trial - Bladder function.

Journal of Pediatric Urology, 13, 139-145

III. J Nordenström, S Sjöström, U Sillén, R Sixt, P Brandström (2017)

The Swedish Infant High-grade Reflux Trial: UTI and Renal damage.

Journal of Pediatric Urology, (2017) 13, 146-154

IV. J Nordenström, S Sjöström, M Dellenmark Blom

High-grade Vesicoureteral Reflux in Infants - A Focus Group Study of Parents' Experiences. *Submitted.*

**SAHLGRENKA AKADEMIN
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The Swedish Infant High-grade Reflux Trial – and a Focus group study of parents' experiences

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Abstract

Background: Vesicoureteral reflux (VUR) is a pathological back-flow of urine from the bladder to the ureter and renal pelvis. VUR is associated with an increased risk of urinary tract infections (UTI) and renal damages. Infants with congenital high-grade VUR (hVUR) often have dysplastic kidneys with diffuse parenchymal defects and a bladder dysfunction with enlarged bladder and poor emptying ability.

Spontaneous resolution of VUR with increasing age is common in lower grades of VUR, but is rarely seen in high-grade VUR. The goal of all VUR treatment is to prevent UTIs and minimize the morbidity related to investigation and treatment. Surgical intervention – endoscopic treatment (ET) or open surgery – can be indicated in case of repeated UTI recurrences or progress of renal damages during antibiotic prophylaxis.

The aim of this research project was to investigate whether hVUR in infants can be treated with endoscopic injection (ET) and if ET is superior to continuous antibiotic prophylaxis (CAP) in the treatment of hVUR; whether the development of bladder dysfunction during infancy can be prevented by early reflux resolution; and whether early ET reduces the risk of UTIs and renal scarring during follow-up. Lastly, we aimed to describe parents' experiences of CAP, surgical intervention (SI), UTI and renal damage.

The first three papers present the results from the Swedish infant high-grade reflux trial – an open, prospective, randomised, controlled, national, multicentre study in which we compared the outcomes (VUR resolution, bladder function, UTI recurrence and renal scarring) in the two groups (ET vs. CAP). This study did not reveal any differences in bladder function, UTI recurrence or renal scarring between the two treatment groups, despite the superior effect of ET on VUR resolution and the fact that VUR-grade at follow-up correlated with both UTI recurrence and renal deterioration. Although bladder dysfunction could not be prevented by early VUR resolution, it can be seen an important prognostic factor for VUR outcome.

The fourth paper is based on focus group discussions, held with parents of children with infant hVUR, and describes the parents' experiences of the treatment and outcomes. The focus group discussions revealed that both CAP and the risk of UTI have a negative, everyday impact on family life, while renal damage appears to be less important to the parents. The concerns relating to SI are related to one single occasion, which can be optimised by proper care. VUR management should be individualised and risk adapted according to current knowledge and parents' preferences should be considered.

Keywords: Infant, High-grade vesicoureteral reflux, Randomised, Endoscopic treatment, Antibiotic prophylaxis, Renal damage, Urinary tract infection, Bladder function, Parents' experiences, Focus group, Qualitative study