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Health-related quality of life and treatment effects on children with functional incontinence, and their parents

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Abstract *Objective:* To analyze treatment outcomes and the association between treatment effects and health-related quality of life (HRQoL) for incontinent children, and their parents. *Subjects and methods:* Health-related quality of life in 70 consecutively treated children, and their parents, was assessed with the Pediatric Incontinence Questionnaire and the WHO-Quality-Of-Life-BREF questionnaire. This was assessed before and after three months of standardized treatment.

Results: In 44.3% of children, symptoms decreased by 50–89%. After three months of treatment, the HRQoL of children improved significantly. Children with bladder and bowel dysfunction had a significantly lower HRQoL than children with isolated nocturnal enuresis, daytime urinary incontinence or fecal incontinence. Parental HRQoL did not change significantly within three months of treatment. Parents showed a significantly lower mean in the ‘psychological’ domain of the WHO-QoL-BREF questionnaire compared to norms.

Conclusion: Children with different subtypes of incontinence can be treated effectively within three months of therapy. After three months, significant improvements of HRQoL were shown. Parents showed no general reduction in their quality of life (QoL). Specific aspects of parental QoL were impaired, but did not improve during the treatment of their children.

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Introduction

Functional incontinence, including nocturnal enuresis (NE), daytime urinary incontinence (DUI) and fecal incontinence (FI), is common in childhood. According to the International Children's Continence Society (ICCS), NE is defined as 'incontinence occurring during sleep' and has four subforms: primary monosymptomatic NE (PMNE), primary non-monosymptomatic NE (PNMNE), secondary monosymptomatic NE (SMNE) and secondary nonmonosymptomatic NE (SNMNE). The term 'daytime incontinence' (or daytime urinary incontinence, DUI) is chosen, when a child wets while awake [1]. The Rome-III-classification differentiates between functional constipation (with or without FI) and non-retentive FI (incontinence without constipation) from the age of four years onwards, after excluding organic causes [2]. The ICCS suggests the term 'bladder and bowel dysfunction' (BBD) to describe children with a combination of functional bladder and bowel disturbances [1].

Studies have shown that prevalence rates for six to seven-and-a-half year old children are: 9.1–18.2% for NE [3,4], 4.4–16.9% for DUI [3,5] and 1.4–5.4% for FI [6]. Boys are more often affected by NE [4] and FI [6,7]; girls are more affected by DUI [5,7].

The rate of psychological disturbances is increased in children with incontinence: 20–30% in children with NE, 20–40% in children with DUI and 30–50% in children with FI [8].

Additionally, several studies revealed impaired self-esteem and HRQoL in children with different subtypes of incontinence [9–16]. Two studies showed reduced quality of life (QoL) in mothers of children with NE [13,17]. Only a few studies assessed treatment effects on the QoL. Significant improvements in HRQoL of children [13,16] and their mothers [13] have been shown after successful treatment of NE or combinations of NE, DUI and FI.

In the present study, HRQoL of children with different subtypes of incontinence – isolated NE, DUI or FI vs. combined subtypes (i.e. any combination of NE, DUI and FI) – and their parents were assessed before and after three months of standardized therapy.

The following hypotheses were tested:

1. Standardized treatment of NE, DUI, FI is successful within three months.
2. HRQoL is more impaired in children with combined subtypes of incontinence than in children with isolated subtypes.
3. HRQoL of children and their parents improve within three months of standardized treatment.

Subjects and methods

The sample consisted of 70 consecutively treated children (64.3% boys; mean age = 8.7 years, SD = 2.8, range 4.3–15.8 years) and their mothers (or fathers), who presented within a six-month period at a specialized outpatient department for functional incontinence. Inclusion criteria were diagnoses of NE, DUI, FI or any combination according to ICCS-criteria [1] and Rome-III-criteria [2].

Exclusion criteria were an IQ < 70 and an organic disorder. The local ethics committee approved the study. All children received a child psychiatric assessment, physical examination, sonography and uroflowmetry. Parents completed soiling and voiding questionnaires [18,19] and a 48-hour bladder diary for their children [19]. Frequencies of wetting/soiling before and after three months of treatment, as well as treatment effects according to ICCS-criteria were assessed [20] (no response – symptom decrease <50%; partial response – symptom decrease 50–89%; responsive response – symptom decrease ≥90%). A mean of symptom decrease in NE, DUI and FI was calculated for BBD. All children underwent psychometric testing; this included a parental questionnaire [21], a psychiatric interview [22] and an IQ measurement.

HRQoL of children was assessed with the German version of the Pediatric Incontinence Questionnaire (PINQ-D) [23]. In children with FI, items were adapted accordingly. The self-rating version of PINQ-D for children was used; this consists of 21 items of consequences for NE and DUI in daily life and relationships. Answers are scored on a Likert-scale of '0 = no' to '4 = always'. A total sum score was calculated; high scores indicated low HRQoL.

Parental QoL was evaluated with the German version of WHO-Quality-Of-Life-BREF questionnaire, which consists of 26 items on the domains: 'physical health', 'psychological', 'social relations' and 'environment' [24]. A score of 'overall quality of life and general health' was calculated. High *T*-values indicated high QoL.

All children received standardized, evidence-based therapy over three months, which depended on their specific subtype of incontinence [18,19] and included the following components:

Toilet training is the basic therapy for all types of FI. The toilet sessions were documented in charts. In functional constipation with or without FI, laxatives were combined with toilet training [18]. In the treatment of DUI, standard urotherapy (including perception of bladder function, proper toilet posture, scheduled voiding, etc.) is the first-choice of treatment.

In the treatment of urge incontinence a combination with anticholinergics can be indicated. Children with voiding postponement are instructed to go to the toilet at least seven times a day and to note each micturition on a voiding chart. In dysfunctional voiding, the most effective treatment is biofeedback combined with cognitive-behavioral elements. In NE, alarm treatment is the first-line of treatment. If alarm treatment fails or cannot be instituted (due to a lack of motivation or adverse family circumstances), pharmacotherapy (desmopressin) is recommended. All treatment components can be combined with reward systems for compliance [19].

Statistical analysis

Statistical analyses were performed with the PASW statistics version 18 (SPSS Inc., Chicago, IL, USA), using descriptive statistics, nonparametric tests (Chi-squared test, Fisher's Exact test, Mann-Whitney *U* test, Kruskal-Wallis test) and parametric tests (ANOVA, Student's *t*-test for independent and paired samples, one-sample *t*-test, Welch's

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