

Health-related quality of life (QOL) and psychosocial adjustment in children with steroid-sensitive nephrotic syndrome (SSNS)

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Background

- SSNS is a frequent glomerular disease in childhood - incidence: 2-7 cases / 100,000 children
- Up to 50% of patients develop steroid-dependency and require continuous treatment
- Constant fear of a new relapse in children and parents
- Adverse effect of medication (steroids, cytotoxic drugs)



Aims

- Evaluation of QOL in patients and families
 - how do they actually „feel“?
- Evaluation of psychosocial adjustment of the patients
 - how do they „behave“ and „interact“?
- Is medical course of SSNS decisive for psychological outcome?
What influence have factors as number and frequency of relapses?
- **How is influence of family climate on psychosocial adjustment?**



Patients

- 45 patients (31 males) with SSNS
- Age at examination: 9.8 (3.4 to 19.8) years
- Follow-up since onset of SSNS 5.9 (0.1 to 16.3) y
- **Clinical course (definitions according to APN and ISKDC criteria - dies kurz sagen, da nicht alle Exp !):**

No / infrequent relapses	11 ??
Frequent relapsers:	9
Steroid-dependency:	25
Cytotoxic / immunosuppressive / immunomodulatory drugs:	24 / 10 / 6



Methods I

- **QOL:TACQOL =**

- **Child Form:** self-assessment of patients
- **Parent Form:** rating of parents

7 subscales:

- 1) physical complaints, 2) motor functioning,
- 3) autonomy, 4) cognition, 5) social functioning
plus
- 6) positive (happiness, joy) and 7) negative (anger, fear) emotions



Methods II

- **Psychosocial adjustment: CBCL, *Child behavior Checklist & TRF, Teacher Report Form***

Parental and teacher's assessment of child's behavior:

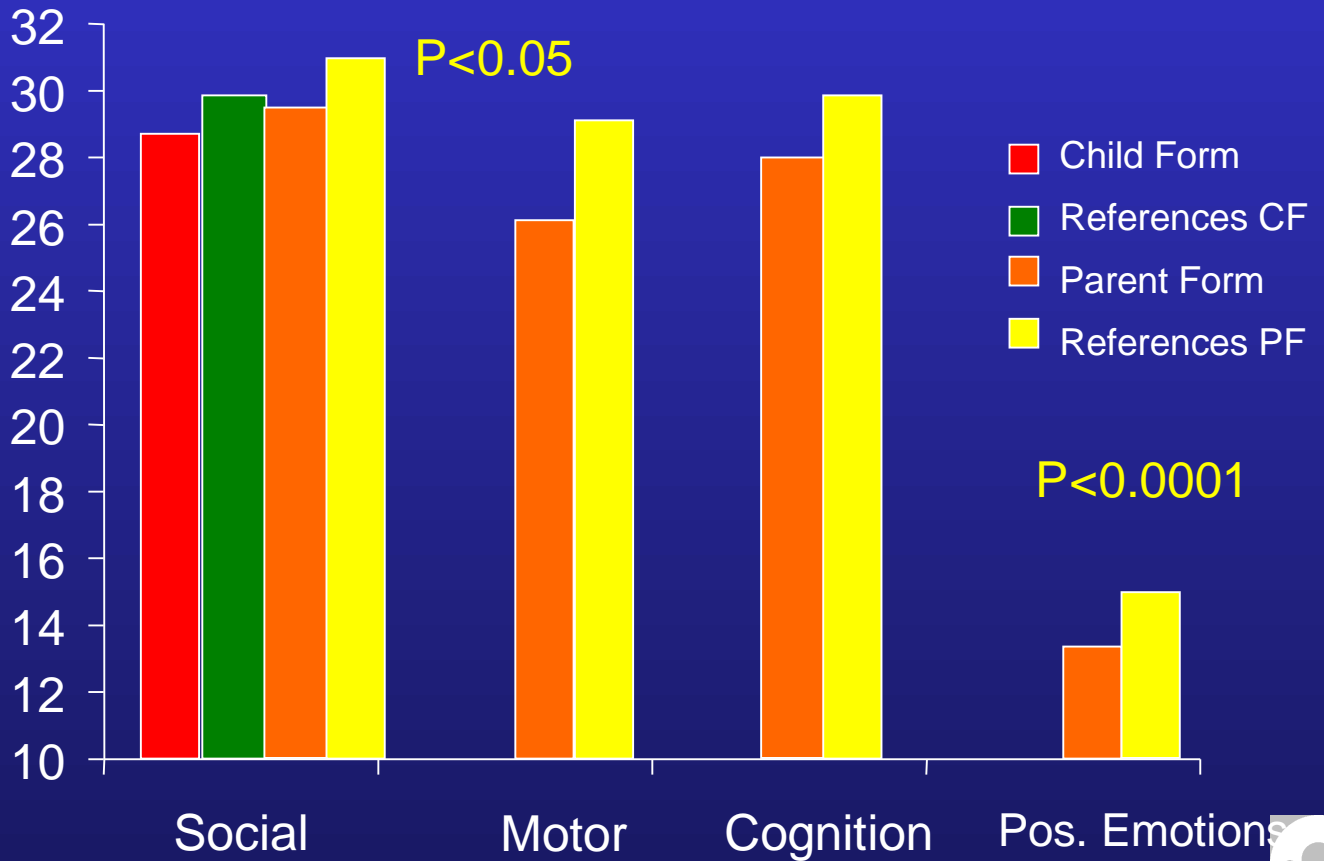
- **Internalising behavior** scales: withdrawn, anxiety/depression, somatic complaints
- **Externalising behavior** scales: social problems, delinquent behavior, aggression, attention problems

- **Parental stress and Family climate (BSI, *Brief Symptom Inventory & FRI, Family Relationship Index***

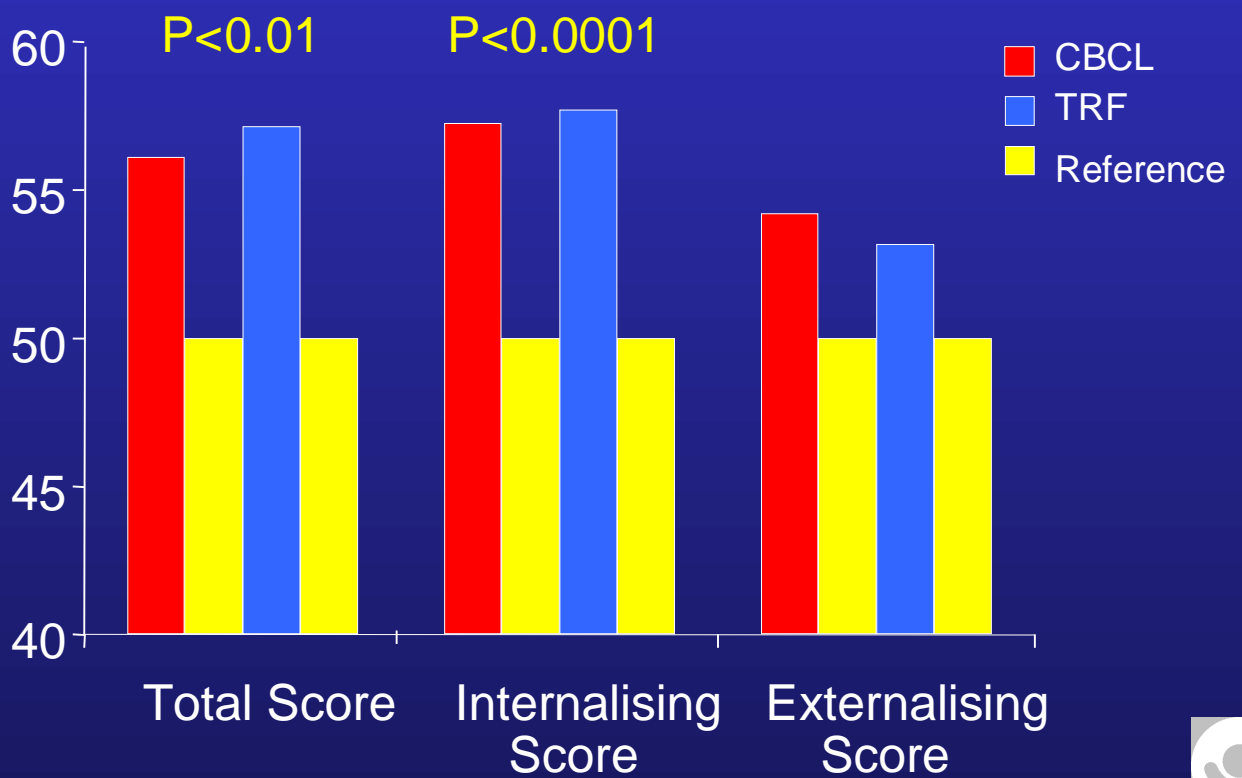


QOL: Quality of life

erklären, dass 32 pt. Maximum = sehr gut.... Warum nur bei social RF ? RF erklären, woher sie stammen warum nur 4 von 7 scales ?



Psychosocial adjustment sagen, dass je besser je weniger Punkte

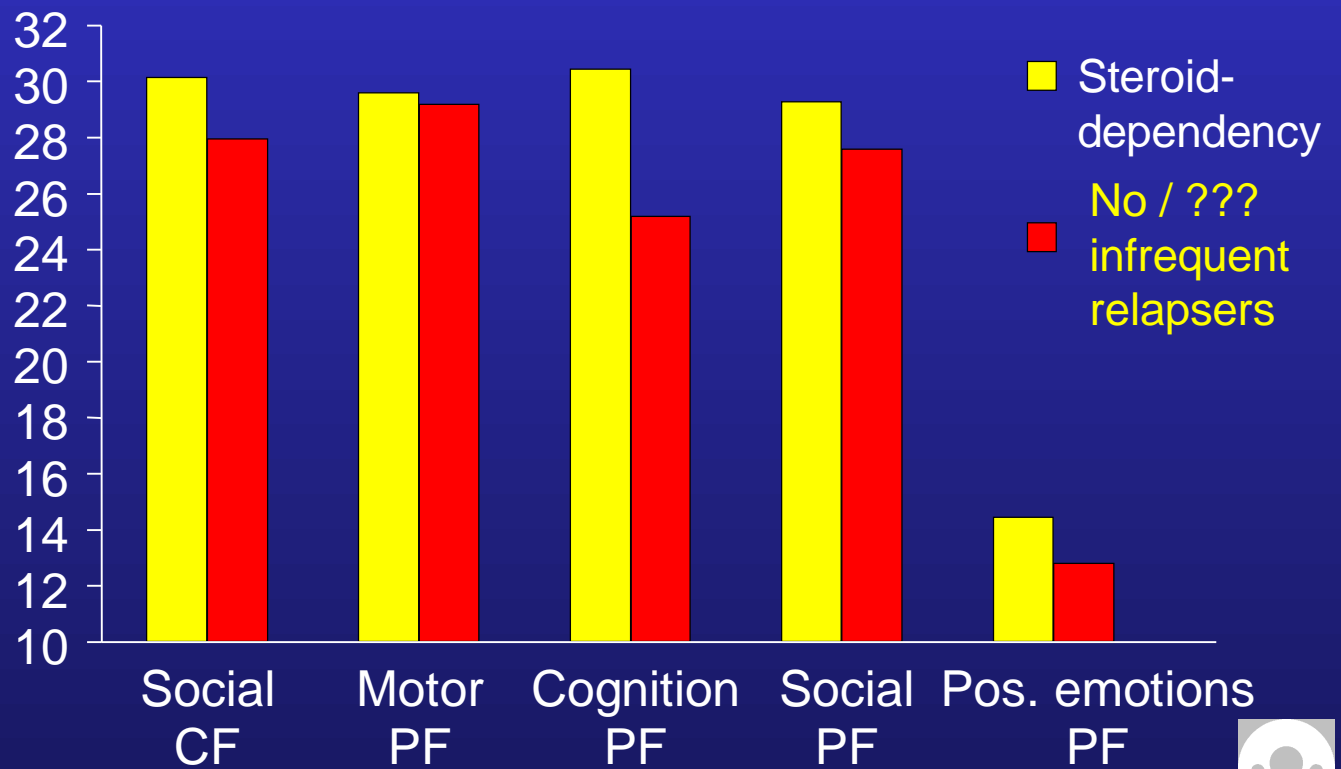


Medical course as predictor of QOL

	Steroid-dependency	Cytotoxic therapy
Child form		
Social	r= -0.35; p<0.05	r= -0.44; p<0.01
Parent form		
Body	r= -0.17; p<0.05	r= -0.36; p<0.05
Cognition	r= -0.16; ns	r= -0.44; p<0.05
Social	r= -0.19; ns	r= -0.33; p<0.05
Emopos	r= -0.35; p<0.05	r= -0.31; ns
Emoneg	r= -0.10; ns	r= -0.33; p<0.05



Medical course and QOL



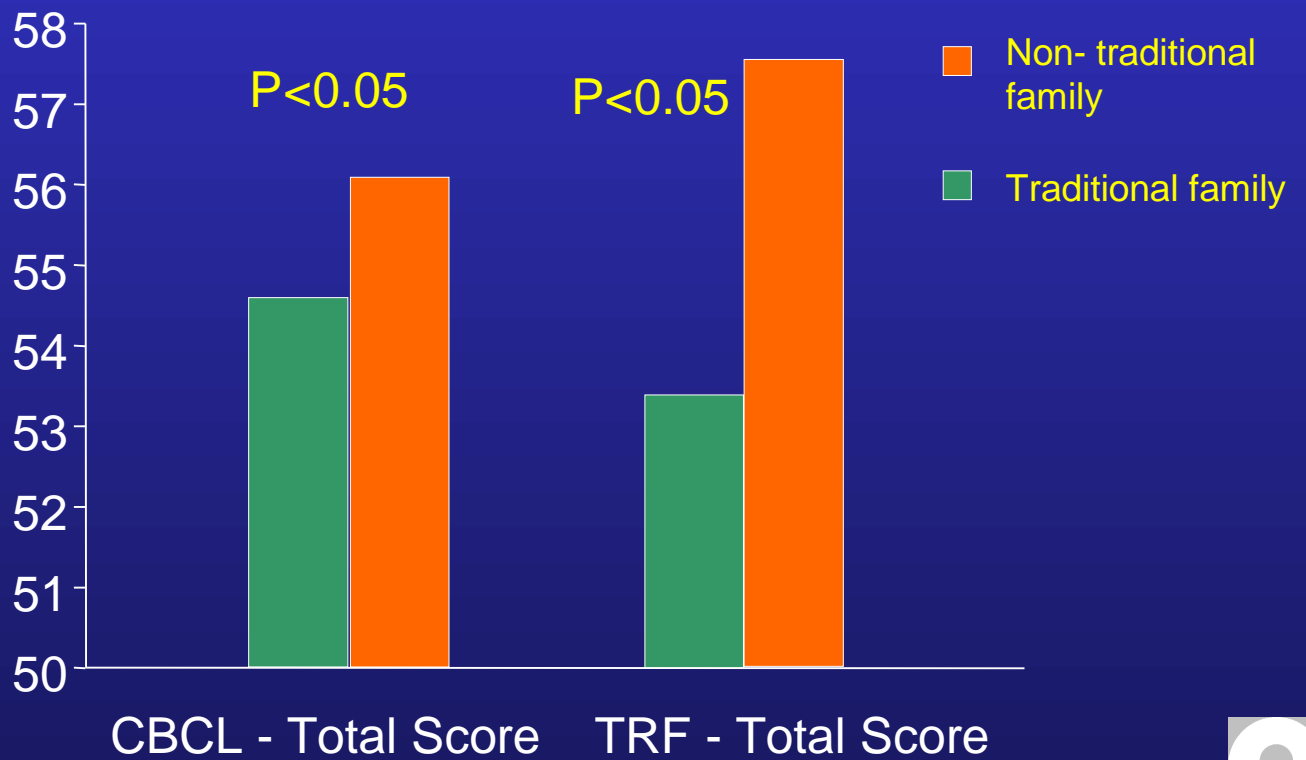
Family climate as predictor for psychosocial adjustment

CBCL	Family situation	Family Relationship	Psychological strain mother	Psychological strain father
Total	$r = -0.35; p < 0.05$	$r = -0.48; p < 0.01$	$r = 0.66; p < 0.001$	$r = 0.54; p < 0.01$
Intern	$r = -0.37; p < 0.05$	$r = -0.41, p < 0.05$	$r = 0.72; p < 0.001$	$r = 0.52, p < 0.01$
Extern	$r = -0.26; ns$	$r = -0.40, p < 0.05$	$r = 0.61, p < 0.001$	$r = 0.54; p < 0.01$

TRF	Socioeconomic status	Family situation (traditional/non-traditional)
Total	$r = -0.46; p < 0.01$	$r = -0.35; p < 0.05$
Intern	$r = -0.27; ns$	$r = -0.37; p < 0.05$
Extern	$r = -0.39; p < 0.05$	$r = -0.26; ns$



Family structure and psychosocial adjustment



Conclusions I: Quality of life (QOL)

- Patients report their QOL as satisfactory except for **social functioning**
- Parents are more discerning:
Impaired rating of their children regarding **social** and **cognitive** functioning, **motor** abilities and **positive emotions**
- **QOL is influenced by course / severity of SSNS:**
Negative influence of steroid-dependency and cytotoxic treatment on QOL



Conclusions II: Psychosocial adjustment

- Psychosocial adjustment is impaired in children with SSNS:
reported not only by parents but also by teachers
- Psychosocial adjustment is influenced by
 - family climate, i.e. parental stress
 - family structure (traditional vs. non-traditional)



Consequences?!

Patients with SSNS do need **psychosocial support**,

if

they have a **severe course of the disease**

or

the socio-economic status of the family is low
and/or the **family structure is unstable.**

