

Steroid-sensitive Nephrotic Syndrome as a psychosocial burden-Long-term analysis

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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
- Adverse effect of medication (steroids, cytotoxic drugs)
- Cross-sectional analysis showed an increased psychosocial burden and behavioral problems, especially in patients with a more severe course

Aims

- Re-Evaluation of the psychosocial adjustment of the patients
 - how do they „behave“ and „interact“?
- Evaluation of the long-term changes in our well-described patient group
- Is the medical course of SSNS (still) decisive for their psychological outcome?

Patients

- Gender (female/male) 12/28
- Age at follow-up (years) 10.6 ± 3.2 (4.7-20.4)
- Time between 1st evaluation and follow-up (months) 9.0 ± 1.1 (7.0-12.9)
- Time since onset of SSNS (years) 6.6 ± 3.6 (0.8-16.9)
- Number of relapses between evaluations 0 (0-6)
- Steroid dependency at follow-up (no/yes) 32/8
- Steroid therapy at follow-up (no/yes) 27/13
- Cytotoxic / immunosuppressive / immunomodulatory drugs (no/yes) 28/12
(cyclophosphamide, chlorambucil, each n=1, levamisole n=2, cyclosporine A n=8)

Quality of Life: TACQOL, TNO-AZL *Child quality of life* questionnaire

- 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) emotions
 - 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:

- Internalizing behavior scales: withdrawal, anxiety/depression, somatic complaints
- Externalizing behavior scales: social problems, delinquent behavior, aggression, attention problems

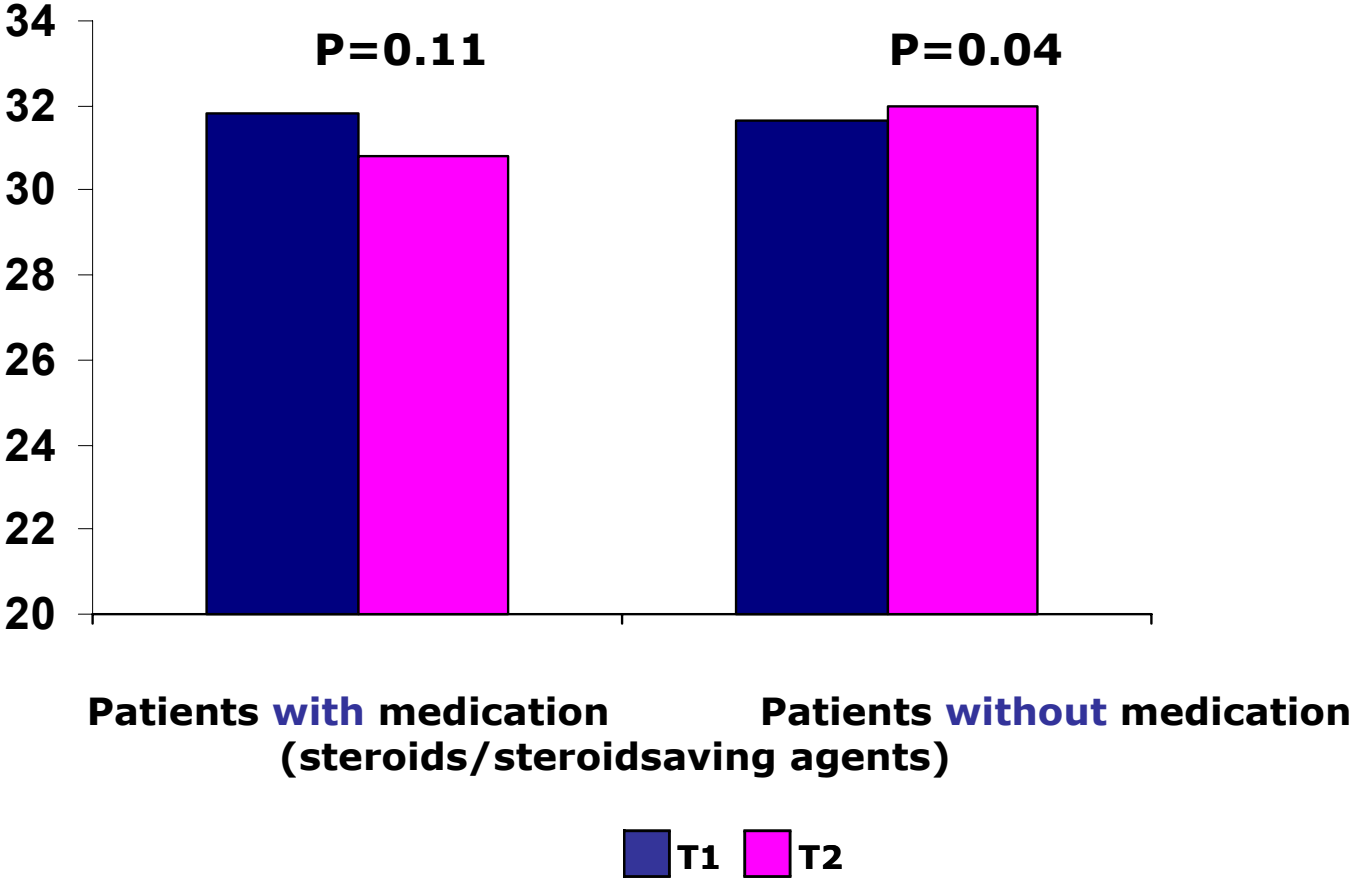
Review of Results of cross-sectional evaluation

- 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**
- **Negative influence of steroid-dependency and cytotoxic treatment on QOL**
- **Psychosocial adjustment is impaired in children with SSNS: reported not only by parents but also by teachers**

Results I – Quality of Life

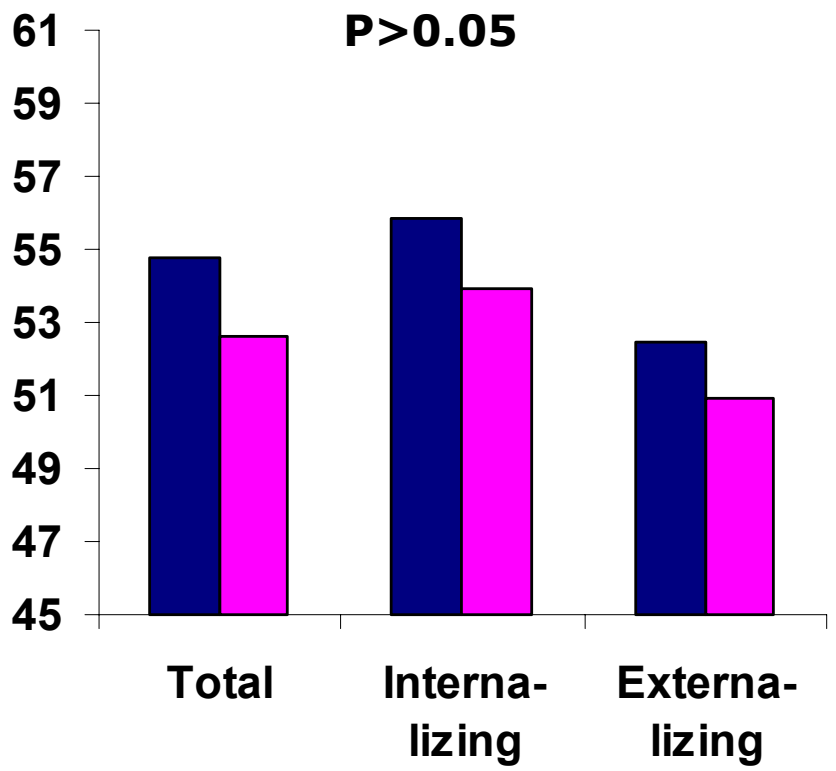
TACQOL-Child Form

Autonomy

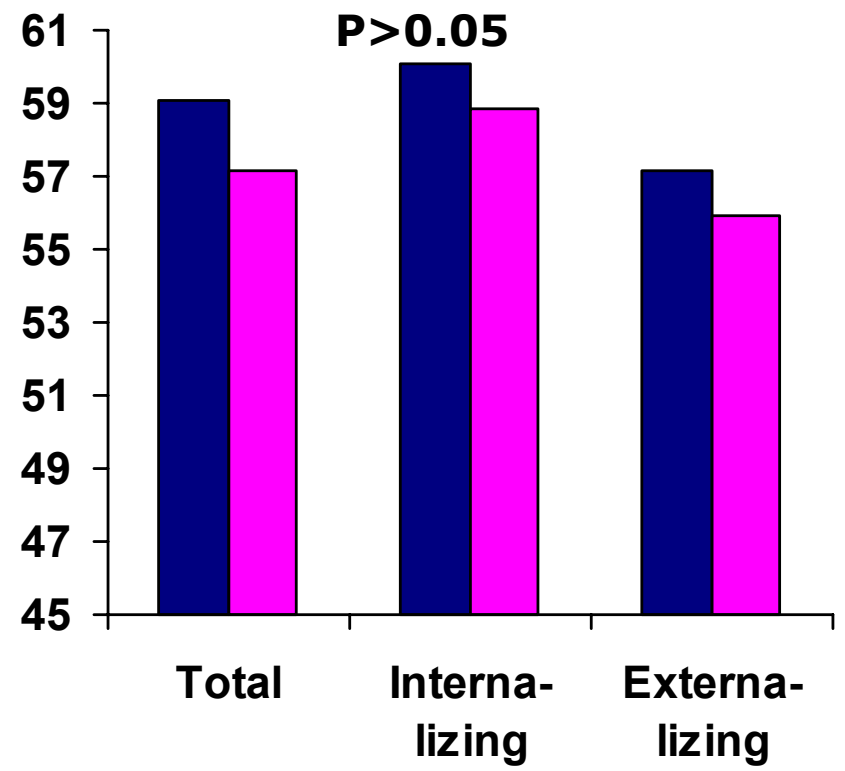


Results II – Psychosocial adjustment Child Behavior Checklist

**Patients with medication
(steroids/steroidsaving agents)**



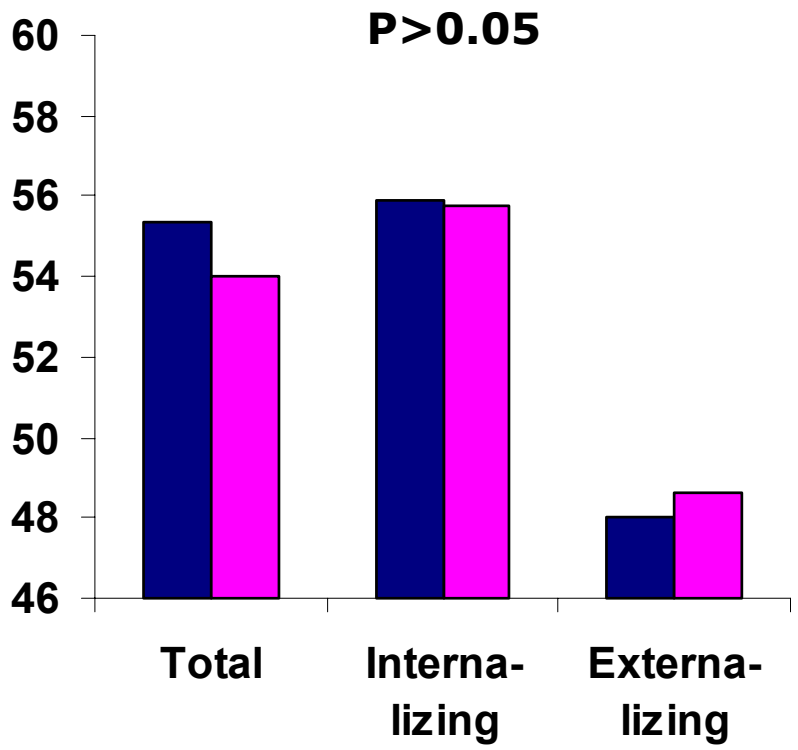
**Patients without medication
(steroids/steroidsaving agents)**



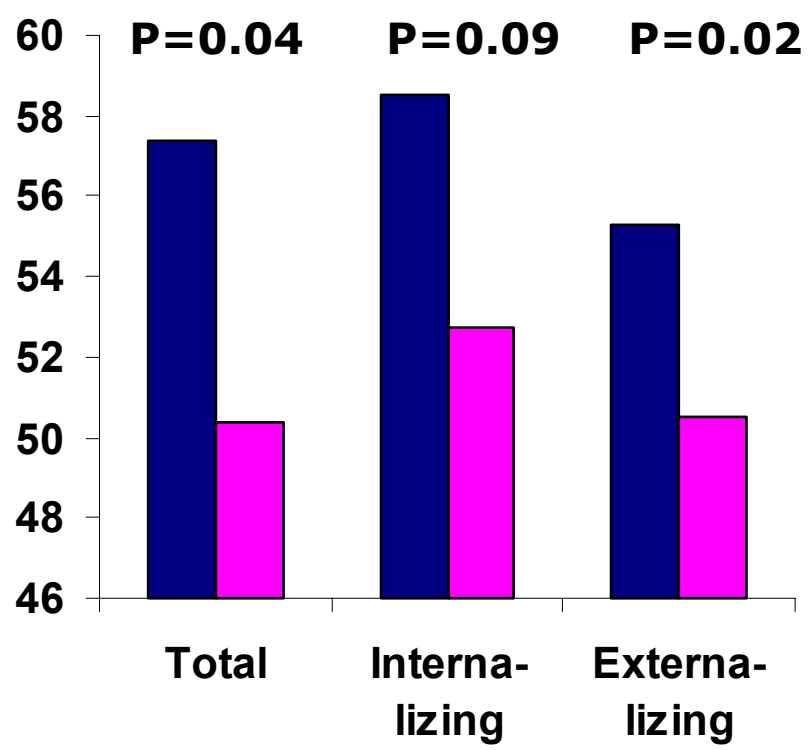
■ T1 ■ T2

Results III – Psychosocial adjustment Teacher Report Form

**Patients with medication
(steroids/steroidsaving agents)**



**Patients without medication
(steroids/steroidsaving agents)**



■ T1 ■ T2

Summary and Conclusion

- Quality of life (self- and parental assessment) does not show any correlation to the medical course
- Long-term analysis confirms the psychosocial burden of patients with steroid-sensitive nephrotic syndrome
- Patients with a **milder course of SSNS** , i.e. no necessity for drug therapy are evaluated **more positive by parents**
- Patients without any drug therapy are **evaluated best by their teachers**
- The different judging of parents and teachers might be due to a more objective view of the teachers