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  - *Internalising behavior* scales: withdrawn, anxiety/depression, somatic complaints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?

P < 0.05

P < 0.0001
Psychosocial adjustment sagen, dass je besser je weniger Punkte.
### Medical course as predictor of QOL

<table>
<thead>
<tr>
<th></th>
<th>Steroid-dependency</th>
<th>Cytotoxic therapy</th>
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<td><strong>Child form</strong></td>
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<tr>
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<td><strong>Parent form</strong></td>
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<tr>
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<td>r = -0.31; ns</td>
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Medical course and QOL

- **Steroid-dependency**
  - No / ???
- **Infrequent relapsers**

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<th>Value</th>
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<td>Pos. emotions PF</td>
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Family climate as predictor for psychosocial adjustment

<table>
<thead>
<tr>
<th></th>
<th>Family situation</th>
<th>Family Relationship</th>
<th>Psychological strain mother</th>
<th>Psychological strain father</th>
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<th>Family situation (traditional/non-traditional)</th>
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<tr>
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<td>r= -0.26; ns</td>
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</table>
Family structure and psychosocial adjustment

CBCL - Total Score  TRF - Total Score

P<0.05  P<0.05

Non- traditional family  Traditional family
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.