Health-related quality of life in children with chronic kidney disease, comparisons between parent and child reports

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Previous work

- We evaluated HRQoL in children and adolescents with CKD or CKD-T...
Aim

- To study the parents view on HRQoL of their children with CKD or CKD-T and to compare this with the children’s reports

- To study effects of possible risk predictors such as gender, age, underlying CKD status on HRQoL

- Associations between the child’s HRQoL and the parent’s own life satisfaction/QoL were also searched for
Participants

- 60 parents to 64 children with CKD stage 3-5 or CKD-T
  - 2 of parents refused, 2 had other commitments
  - 25 patients with CKD, 35 with CKD-T
  - Age of children, mean 14 yrs +/- 3.3 (8.0-19.1)

- Design
  - Cross-sectional study
Assessment

- HRQoL questionnaires
  - Kidscreen-27, parent form
    - Generic QOL instrument
    - Five dimensions
  - Disabkids-37, parent form
    - Generic QOL instrument
    - Six dimensions
Kidscreen-27, parent form

Subscales:
1. Physical activities and health
2. General Mood and Your Child’s Feelings
3. Family and Your Child’s Free Time
4. Friends
5. School and Learning
Disabkids-37, parent form

Subscales:
1. About your child’s life
2. About your child’s typical day
3. About the way your child feels
4. About your child and other people
5. About your child’s friendships
6. About your child’s medical treatment
LiSat-11

- self-report to measure parental life satisfaction in nine different domains and in satisfaction with life as a whole
Results: Kidscreen-27

HRQoL according to the self and parent proxy assessments

Expected norm values
Mean = 50
SD = 10

Ph = Physical Well-being, Pw = Psychological Well-being, Pa = Autonomy & Parent relation
Pe = Social support & Peers, Sc = School
Results: Disabkids-37

HRQoL according to the self and parent proxy assessments

Ind = Independence, Phy = Physical limitation, Emo = Emotion, Excl = Social exclusion, Incl = Social inclusion, Med = Treatment, Gen = DCGM-37 Total score
Results

- Parent proxy ratings were lower in five out of six Disabkids-37 subscales and in General scale compared to children (all $p$’s < 0.001)

- Parent proxy ratings were significantly lower in subscales *Social exclusion* and *Social inclusion* and in General scale compared to European parent proxy ratings

- Female sex and older age were associated with lower HRQoL in dimensions Emotional well-being and Social inclusion

- Parent proxy ratings did not differ between categories CKD 3 to 5 and CKD-T
Results: LiSat-11

Life satisfaction of parents as assessed by LiSat-11 compared with Swedish norm population (Fugl-Meyer et al. 2002)
Results
Correlation between parents’ life satisfaction and HRQoL of children as rated by parent proxy

- Disabkids-37 (proxy) Total score (mean)
- LiSat-11 score (mean)

$r = 0.33$
$p = 0.01$
$n = 60$
Conclusions

- Agreement between parent proxy and child reports of HRQoL was generally poor, parents as informants reported lower HRQoL in their children.

- Parent ratings of HRQoL in children with CKD seemed to correlate with parents own life satisfaction.

- Differences between parent and child ratings should be considered in clinical practice.
Thank you for your attention!