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# **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...

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REGULAR ARTICLE

## Associations between lower urinary tract dysfunction and health-related quality of life in children with chronic kidney disease

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**Keywords:**  
Bladder dysfunction, Chronic kidney disease, Health-related quality of life, Kidney transplant, Lower urinary tract symptoms.

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**ABSTRACT**

**Aim:** Little is known about the health-related quality of life (HRQoL) of children with lower urinary tract dysfunction (LUTD) and chronic kidney disease (CKD). We investigated LUTD and other possible predictors of impaired HRQoL in children with conservatively treated moderate-to-severe CKD or with a kidney transplant.

**Methods:** All 64 children with CKD or a kidney transplant treated at Karolinska University Hospital, Stockholm, Sweden, between June 2011 and December 2012 were approached and 59 children aged 8–18 were enrolled in the study. Lower urinary tract function was evaluated with voiding history, frequency and volume chart, uroflowmetry and postvoid ultrasound measurements. Self-reported HRQoL was assessed with validated generic instruments.

**Results:** The HRQoL of the study cohort was as good as the general paediatric population, apart from the physical and psychological well-being dimensions, and was no different to children with other chronic conditions. Urinary incontinence, but not LUTD in general, was associated with impaired HRQoL, as was having a kidney transplant and being female in some dimensions.

**Conclusion:** LUTD was common in children with CKD or a kidney transplant but did not affect their general HRQoL. Predictors of impaired HRQoL included incontinence, having had a kidney transplant and being female.

**INTRODUCTION**

Living with paediatric chronic kidney disease (CKD) is still associated with risks for complications requiring lifelong management (1). Optimal care to prevent or delay the progress of CKD places demands on medical staff and on the psychosocial management of the everyday lives of these children and their families (2,3).

Approximately one-third of paediatric CKD cases are caused by urological abnormalities and are often associated with lower urinary tract dysfunction (LUTD) (4). Early attention and better understanding of LUTD, together with improvements in surgical interventions, have improved graft survival after renal transplantation in this subgroup of patients (5). However, signs and symptoms consistent with LUTD, such as large maximum voided volumes, postvoid residual urine and incontinence, are also common in children with CKD without urological abnormalities (6). The underlying mechanisms in these patients are unknown, but possible reasons could be long-standing effects of oliguria or polyuria. Incontinence, which might be an explicit sign of LUTD, is known to be associated with an impaired HRQoL and lower self-esteem in healthy children (7). Both children with conservatively treated CKD and paediatric renal transplant recipients with signs of LUTD are routinely prescribed bladder training regimens in order

**Abbreviations**

CKD, Chronic kidney disease; DCGM-37, DISABKIDS Chronic Generic Module-37; ESRD, End-stage renal disease; GFR, Glomerular filtration rate; HRQoL, Health-related quality of life; LUT, Lower urinary tract; LUTD, Lower urinary tract dysfunction; QoL, Quality of life.

**Key Notes**

- Little is known about health-related quality of life (HRQoL) in children with lower urinary tract dysfunction (LUTD) and chronic kidney disease (CKD).
- Our Swedish study of 57 children aged 8–18 showed impaired physical and psychological well-being in children with CKD or a kidney transplant compared to the general paediatric population.
- Predictors of impaired HRQoL included incontinence, having had a kidney transplant and being female.

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959

## 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

### 1. Physical Activities and Health

**In general, how would your child rate her/his health?**

1.

excellent

very good

good

fair

poor

**Thinking about the last week ...**

	not at all	slightly	moderately	very	extremely
2. Has your child felt fit and well?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Has your child been physically active (e.g. running, climbing, biking)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Has your child been able to run well?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Thinking about the last week ...**

	never	seldom	quite often	very often	always
5. Has your child felt full of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### 2. General Mood and Your Child's Feelings

**Thinking about the last week...**

	not at all	slightly	moderately	very	extremely
1. Has your child felt that life was enjoyable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Thinking about the last week...**

	never	seldom	quite often	very often	always
2. Has your child been in a good mood?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Has your child had fun?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# 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



### About your child's typical day

Think about the past four weeks!

never	seldom	quite often	very often	always
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7.	Does your child feel able to run and move as he/she likes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Does your child feel tired because of their condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Does your child feel that their life is ruled by their condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Does it bother your child that they have to explain to others what they can and can't do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Does your child find it difficult to sleep because of their condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Does your child's condition bother them when they play or do other activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



### About the way your child feels

Think about the past four weeks!

never	seldom	quite often	very often	always
-------	--------	-------------	------------	--------

13.	Does your child's condition make them feel bad about themselves?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	Does your child feel unhappy because of his/her condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	Does your child worry about his/her condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	Does your child's condition make him/her angry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	Does your child have fears about the future because of his/her condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	Does your child's condition get him/her down?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	Does it bother your child that his/her life has to be planned?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

DISABKIDS © - Chronic Generic Module - Parent Version (young people aged 8-18) page 3

# Lisat-11

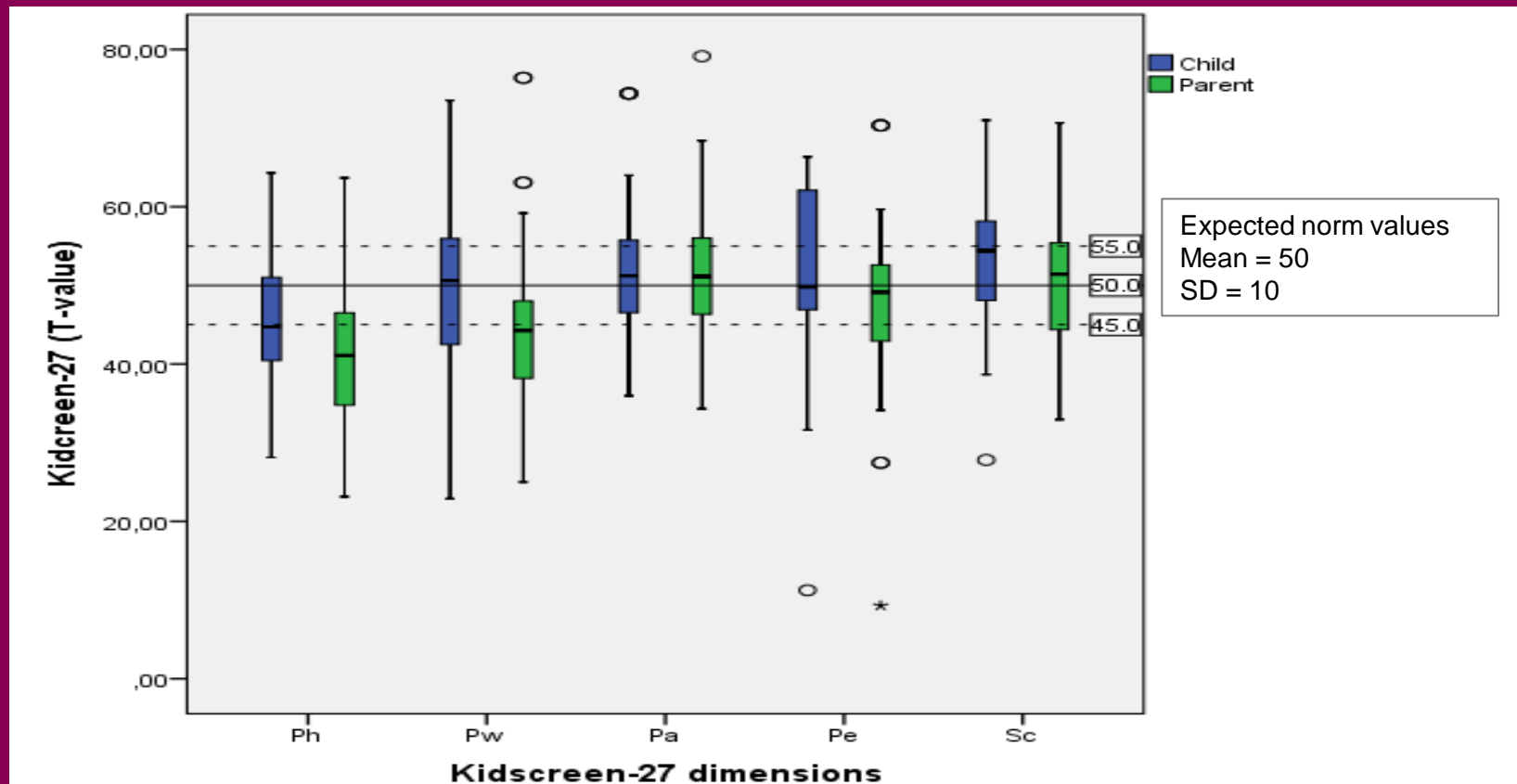
## LiSat-11

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



# Results: Kidscreen-27

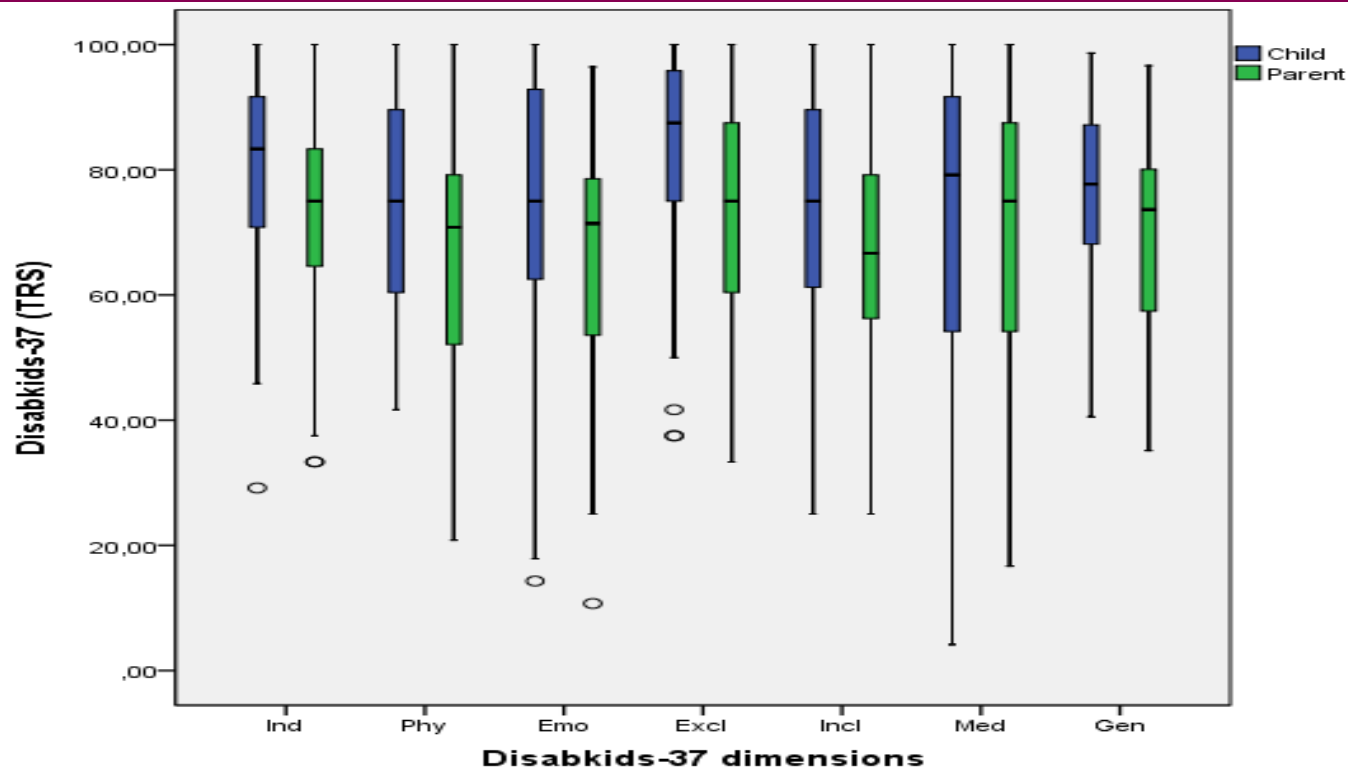
HRQoL according to the self and parent proxy assessments



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



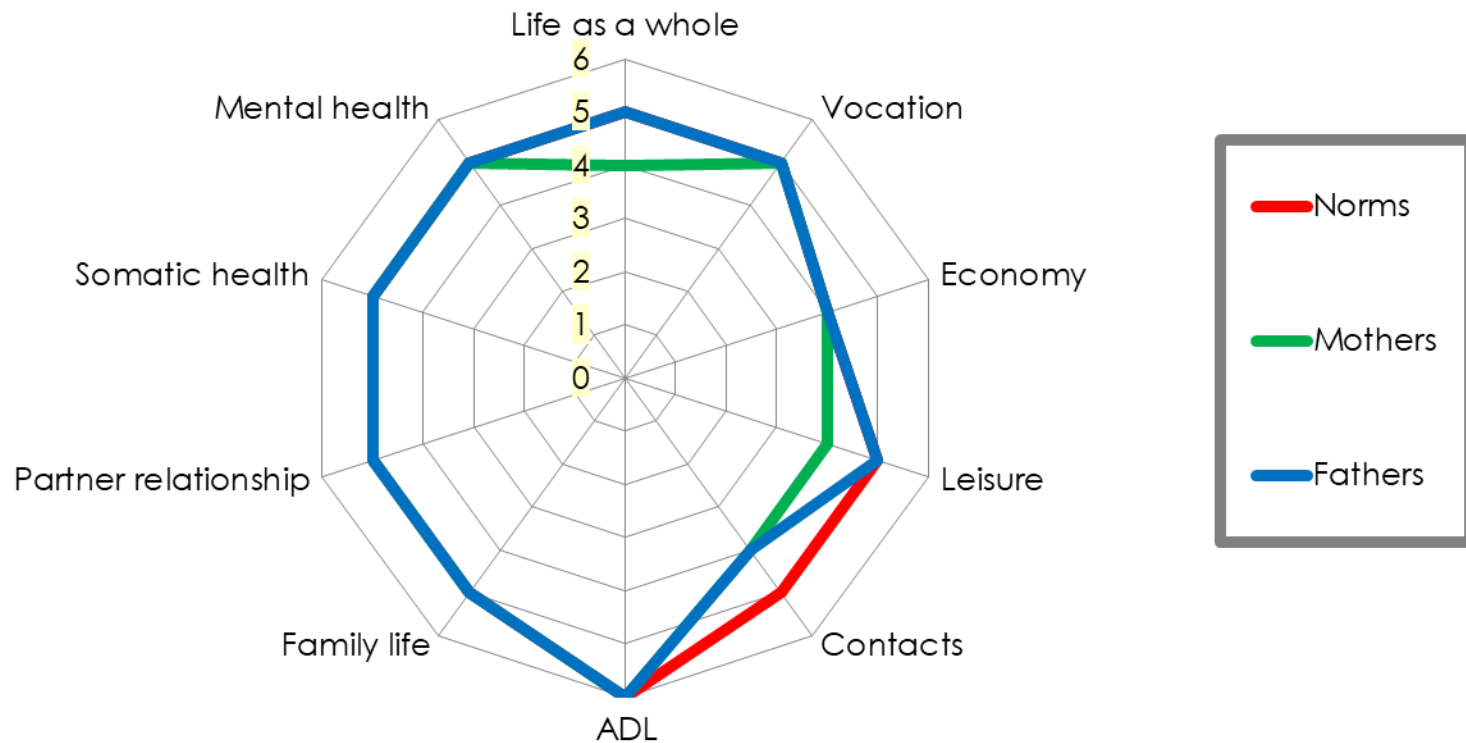
Ind = Independence, Phy = Physical limitation, Emo = Emotion, Excl = Social exclusion,  
Incl = Social inclusion, Med = Treatment, Gen = DCGM-37 Total score

## 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

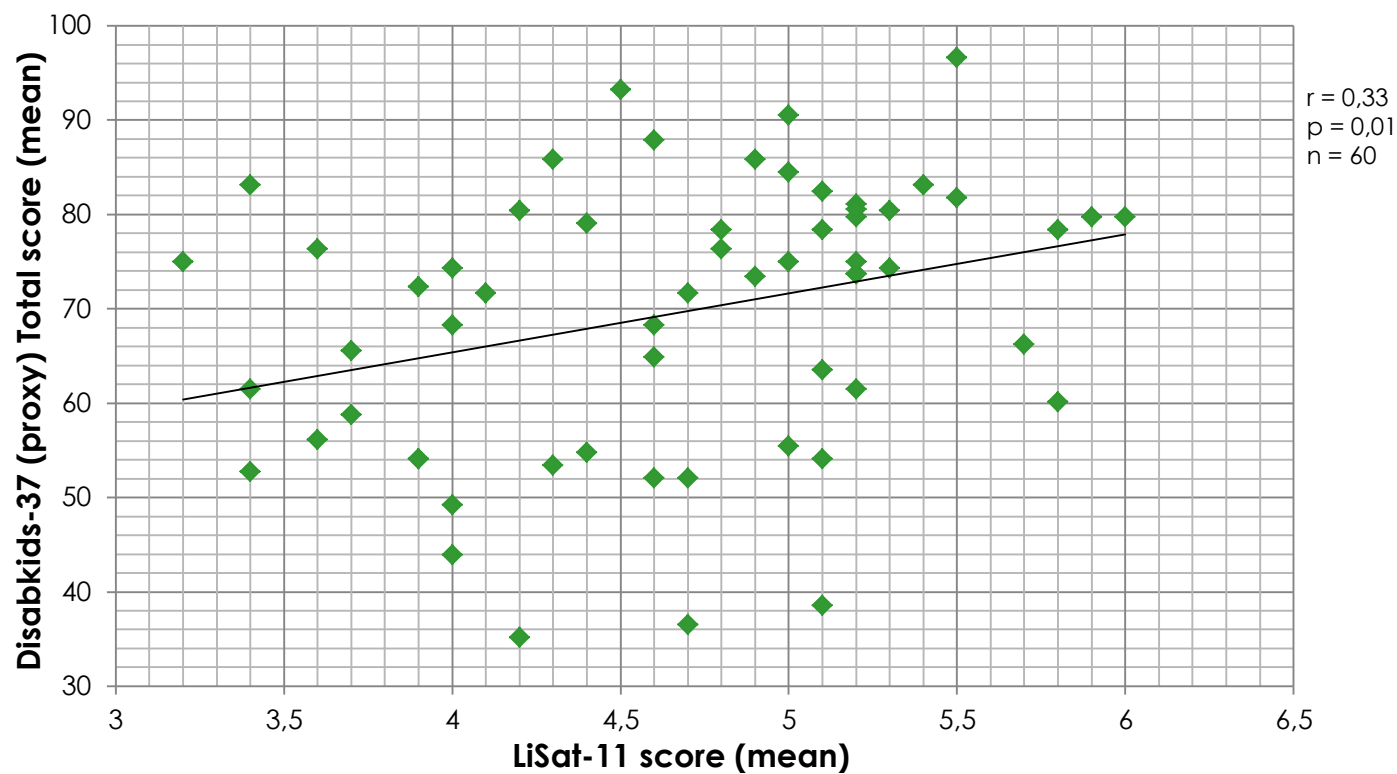
# Results: LiSat-11

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



# 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!