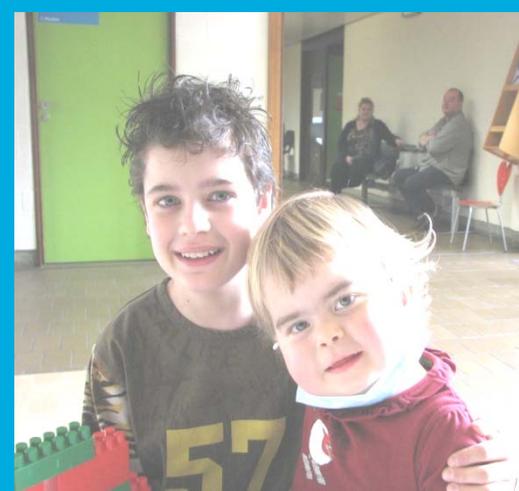


# Comparison of quality of life perceptions between adolescent renal transplant patients, their parents and healthy controls a perfect match?



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Pediatric renal transplantation (RTx) is expected to improve the quality of life (QOL) of patients.

Adolescents are challenged with many difficult developmental tasks on top of coping with a chronic disease, which may affect their QOL.

### Most studies

- Did not study QOL in adolescents separately
- Did not compare their scores with those of healthy controls
- Use parent report instead of directly questioning the adolescent

- . To evaluate QOL from the perspective of both the adolescent patients and the parents
- . To compare scores with norm data for healthy controls

cross-sectional study

consecutive sample of adolescent kidney tx patients and their parents

Measurement:

Demographic characteristics: semi-structured interview with patients

Quality of life: Kidscreen-27

- Instrument to assess generic health-related QOL in children age 8-18
- 27 items representing 5 dimensions of QOL
  - » Physical well-being
  - » Psychological well-being
  - » Autonomy and parent relationship
  - » Social support and significant others
  - » School
- Reliability and validity of the existing translations is excellent

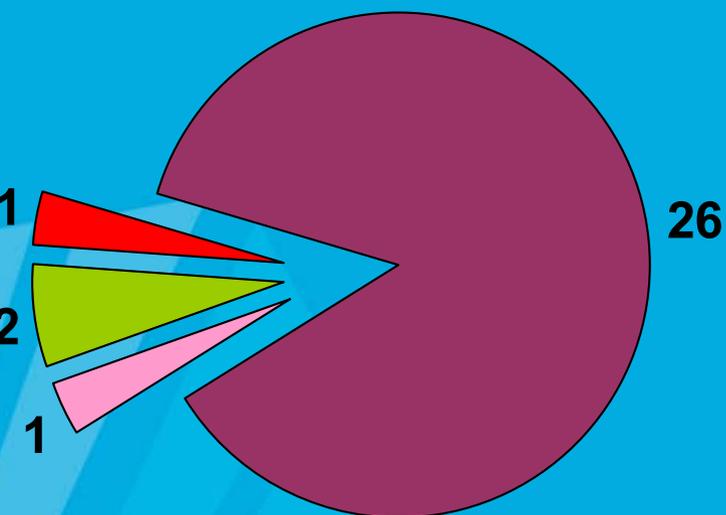
Study explained by an independent researcher in a standardized way to patients and parents together

Informed consent obtained from patient & parent

Patients and parents were interviewed and completed the kidscreen-27 independently in separate rooms

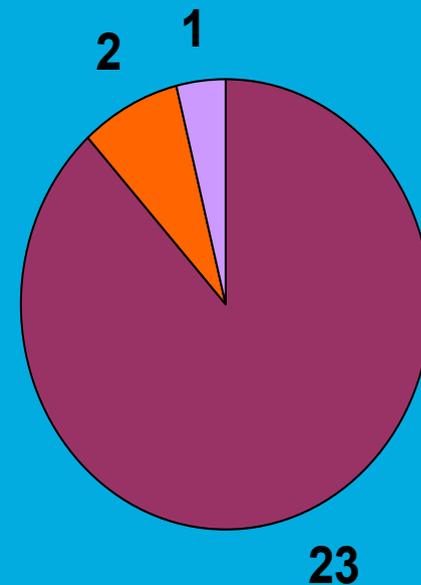
All questionnaires were coded to guarantee privacy

0 adolescent (10-18 years)  
patients in follow-up



not dutch  
mentally retarded  
met inclusion criteria  
too ill to complete the questionnaires

Participation rate (88.4%)



informed consent  
time constraints  
psychological problems

## Demographic and clinical characteristics

Median age in years (Q1; Q3)	15 (range 11-19)
Gender (% female)	7 (30.0%)
Living situation:	
With both parents	19 (82.6%)
Alternating with mother and father	3 (12.7%)
With mother alone	1 (4.3%)
Level of education	
Primary school (%)	3 (12.7%)
Secondary school (%)	19 (82.6%)
Continued education (%)	1 (4.3%)
Median time since Tx in years (Q1; Q3)	3 (range 1-10)
Radaveric transplantation (%)	16 (69.6%)
Immunosuppressive regimen	
Tacrolimus (with or without steroids) (%)	14 (60.9%)
Cyclosporine (with or without steroids) (%)	7 (30.4%)

<p><b>Scales SCREEN-27</b></p>	<p><b>Patients compared to age- and gender matched healthy controls (N=23)</b></p>			<p><b>Parents of Tx patients compared to parents of age- and gender matched healthy controls (=22)*</b></p>			<p><b>Patients versus parents (N=)</b></p>
	<p><b>Scores of Tx patients</b></p>	<p><b>Norm scores</b></p>	<p><b>a</b></p>	<p><b>Scores of TX patients</b></p>	<p><b>Norm scores</b></p>	<p><b>a</b></p>	<p><b>b</b></p>
<p><b>Physical well-being</b></p>	<p>47.08</p>	<p>52.88</p>	<p>p=0.06</p>	<p>52.68</p>	<p>53.19</p>	<p>p=0.60</p>	<p>p=0.</p>
<p><b>Psychological well-being</b></p>	<p>48.45</p>	<p>52.79</p>	<p>p=0.09</p>	<p>44.27</p>	<p>51.23</p>	<p><b>p&lt;0.01</b></p>	<p>p=0.</p>
<p><b>Autonomy and parent relationship</b></p>	<p>51.21</p>	<p>53.95</p>	<p>p=0.14</p>	<p>51.15</p>	<p>53.93</p>	<p><b>p=0.01</b></p>	<p>p=0.</p>
<p><b>Emotional support and significant others</b></p>	<p>53.23</p>	<p>52.36</p>	<p>p=0,19</p>	<p>52.59</p>	<p>53.24</p>	<p>p=0.94</p>	<p>p=0.</p>
<p><b>Global</b></p>	<p>45.38</p>	<p>53.06</p>	<p>p=0.06</p>	<p>46.04</p>	<p>53.11</p>	<p><b>p=0.02</b></p>	<p>p=0.</p>

Our adolescent kidney transplant patients in general rate health-related QOL as satisfactory

The QOL of our patients is comparable to healthy teenagers

Methodological pitfalls:

- Sample size rather low
- Multiple tests => inflation of the type I error
- only adolescents

➤ The results should be interpreted with caution

➤ This study needs to be replicated in a larger sample

- ▶ Adolescents after kidney transplantation are able to live a satisfying life, despite having a chronic illness
- ▶ Given the small sample size, the results should be replicated in larger, prospective studies