

# Outcome after renal transplantation.

## Part II: Quality of life and psychosocial adjustment

Jutta Falger · Markus A. Landolt · Bea Latal ·  
Eva M. R uth · Thomas J. Neuhaus · Guido F. Laube

Received: 18 October 2007 / Revised: 8 February 2008 / Accepted: 8 February 2008 / Published online: 3 April 2008  
  IPNA 2008

**Abstract** Knowledge of health-related quality of life (QOL) and psychosocial adjustment (PA) in children after renal transplantation (RTPL) is limited. QOL and PA were evaluated by standardized tests in patients after RTPL. Thirty-seven children of median age 14.5 years (range 6.5–17 years) were investigated a mean 4.5 years (range 0.5–12.8 years) after RTPL. Child- and parent-rated QOL was evaluated with the Child Quality of life Questionnaire of The Netherlands Organization for Applied Scientific Research Academic Medical Centre (TNO-AZL). PA was assessed by the Child Behaviour Checklist (CBCL) providing parental reports of a child's behaviour. In patients' self-ratings, the QOL dimension physical complaints ( $P<0.0005$ ) scored significantly better than that of healthy controls, whereas the dimension positive emotional functioning was impaired ( $P=0.02$ ). Parents rated motor functioning ( $P=0.002$ ), autonomy ( $P=0.01$ ), cognition ( $P=0.04$ ) and positive emotions ( $P<0.0005$ ) as significantly impaired. Parents also assessed PA significantly ( $P=0.02$ ) impaired with regard to internalizing behaviour. Dialysis duration, young age at RTPL, living-related donation, steroid treatment, adverse family relationships and maternal

distress had a significantly negative impact on QOL and PA ( $P<0.05$ ). Patients rated QOL higher than did healthy controls. Parents evaluated their children's QOL and PA more pessimistically than did the patients themselves. Both illness-related variables and family environment played an important role.

**Keywords** Renal transplantation · Outcome · Health-related quality of life · Psychosocial adjustment

### Introduction

Renal transplantation (RTPL) is the treatment of choice for children with end-stage renal failure (ESRF). As medical outcome has steadily improved over the past decades, with impressive success [1–3], additional outcome parameters, i.e. neurodevelopmental outcome, health-related quality of life (QOL) and psychosocial adjustment (PA), need to be evaluated.

Quality of life and PA had been investigated in acute or chronic diseases in children, e.g. steroid-sensitive nephrotic syndrome, burn survivors, phenylketonuria or asthma [4–7]. There are only a few studies concerning QOL and PA in children and adolescents with chronic kidney disease [8], after RTPL [9–12] or both [13, 14]. In 78 patients with chronic kidney disease aged 11 years to 18 years, a decline in renal function was associated with a subsequent impairment of QOL, particularly in terms of physical activity [8]. Qvist et al. indicated a significantly lower QOL in children who had received transplants when under the age of 5 years [9]; after kidney or liver transplantation, adolescents reported concern about their body or health, less pleasure than ordinary adolescents and poor relationships with peers [10]. In comparison to before RTPL, QOL was significantly

---

J. Falger · E. M. R uth · T. J. Neuhaus · G. F. Laube ( )  
Nephrology Unit, University Children's Hospital,  
Steinwiesstrasse 75,  
8032 Zurich, Switzerland  
e-mail: [guido.laube@kispi.uzh.ch](mailto:guido.laube@kispi.uzh.ch)

M. A. Landolt  
Department of Psychosomatics and Psychiatry,  
University Children's Hospital,  
Zurich, Switzerland

B. Latal  
Child Development Centre, University Children's Hospital,  
Zurich, Switzerland

improved thereafter in 68 paediatric renal transplant recipients [12]. However, these studies differed in their methodology, and illness-related variables and psychosocial determinants of QOL were not systematically evaluated.

Previous studies on PA in children with ESRF [15] and after RTPL [9, 16] most often considered children's self rating [15, 16]. The total scores of the PA did not differ between children after RTPL and healthy controls, but patients with impaired scores had significantly more comorbidities [9]. Mothers rated the PA of their children as impaired, indicating behavioural problems [15]. Children after RTPL assessed their PA as normal; only a few described impairment concerning emotional and psychosocial adaptation [16]. With regard to determinants of PA, child behaviour was negatively influenced by family conflicts [17], underlying disease and co-morbid disabilities [9].

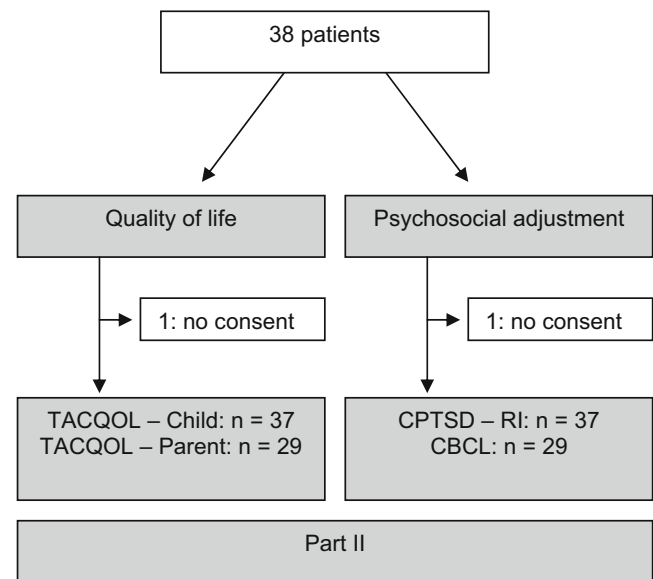
The aim of our study was a comprehensive evaluation of both QOL and PA in children and adolescents after RTPL by use of standardized questionnaires for patients and parents. Additionally, medical, socioeconomic and family-related predictors of QOL and PA were identified. The hypothesis to be tested in this study was that QOL and PA are impaired in children after RTPL in comparison with those in healthy controls and that both illness-related variables and family climate determine QOL and PA.

## Methods

### Patients

Forty patients underwent RTPL at our hospital between 1995 and 2005. Inclusion criteria were follow-up at our unit and, for methodological reasons, age between 5 years and 17 years, and sufficient knowledge of the German language. Two patients had died, with good renal graft function, and one patient did not consent. Thus, 37 patients (20 boys, 17 girls) could be studied (Fig. 1).

Underlying diseases were acquired, congenital and inherited in seven, 13 and 17 cases, respectively. Immunosuppression at examination consisted of cyclosporine A ( $n=25$ ; trough level 80–120 ng/ml) or tacrolimus ( $n=12$ ; trough level 4–8 ng/ml), and mycophenolate mofetil ( $n=24$ ; dose 1,200 mg/m<sup>2</sup> body surface area and 900 mg/m<sup>2</sup> body surface area in patients on cyclosporine A and tacrolimus, respectively) or azathioprine ( $n=12$ ; dose 1 mg/kg body weight). Twenty patients were off steroids [18], seven were on daily doses of prednisone (median dose 5 mg; range 2.5–10 mg) and ten were on alternate-day doses of prednisone (median dose 3.5 mg; range 2.5–7.5 mg). One patient was treated only with cyclosporine A and steroids. Renal function was assessed as the glomerular filtration rate (GFR), calculated with the Schwartz-formula [19], using the local  $k$  factor of 40.



**Fig. 1** Algorithm of all 38 surviving patients who had received transplants between 1995 and 2005 included in part II:  $n=37$ . Age at transplantation was 2–15 years; age at evaluation was 6–17 years. *TACQOL* The Netherlands Organization for Applied Scientific Research Academic Medical Centre (TNO-AZL) Questionnaire for Children's Health-Related Quality of Life, *CPTSD-RI* childhood post-traumatic stress disorder-reaction index, *CBCL* child behaviour checklist

Seventeen patients attended ordinary schools. Six patients each went to a special-needs school or a private school. Six adolescents had started their vocational training; two young children attended a nursery.

### Measurements

#### *TNO-AZL questionnaire for children's health-related quality of life*

The Netherlands Organization for Applied Scientific Research Academic Medical Centre (TNO-AZL) Child Quality of Life Questionnaire (TACQOL) [20] offers a children's form and a parents' form, designed to assess the QOL in children with chronic diseases aged 8 years to 15 years. Both forms contain seven scales assessing physical complaints (Body), basic motor function (Motor), autonomy (Auto), cognitive (Cognition), social functioning (Social), global positive emotional functioning (Emotion positive) and global negative emotional functioning (Emotion negative). The questionnaire asks for problems in any of the above-mentioned areas. If reported, the child's emotional response to the problem was assessed. The items were scored on a 0–4 point scale (4=problem never occurred; 3=problem occurred, but child felt good; 2=problem occurred, but child felt not so well; 1=problem occurred, child felt rather bad; 0=problem occurred, child felt bad). Maximum domain scores are 32 for

the first five domains and 16 for the emotional scales. Higher scores represent better QOL.

Studies with normal and clinical samples confirmed the internal and external validity for the questionnaires [20, 21]. Normal values for the children's form were provided by over 2,300 healthy Dutch children aged 8–15 years (communicated by A.G.C. Vogels, 15 Sept 2006). Reference values for the parents' form were retrieved from the scale manual [20]. They were based on data from 1,618 parents of healthy children aged 6–11 years.

#### *Child behaviour checklist*

The Child Behaviour Checklist (CBCL) [22, 23] is a standardized measure with excellent psychometric properties providing parental reports of a child's behaviour. It consists of 120 items assessing internalizing (withdrawn, somatic complaints, anxiety/depression, thought problems) and externalizing (social problems, attention problems, delinquent and aggressive behaviour) behaviour problems. From these problem scales, a Total Behavioural Problem score is calculated and compared with age- and gender-matched normative data (T-scores). Reference values are provided by 2,856 healthy German children and adolescents aged 4 years to 18 years [5, 6]. Higher scores indicate impaired child behaviour.

#### *Brief symptom inventory*

The Brief Symptom Inventory (BSI) is a 53-item, self-report questionnaire describing symptoms of psychological distress, anxiety and depression in adults [24]. In this study, only the global severity index (GSI) assessing parents' overall mental health was used. Psychometric properties of the BSI are adequate in terms of convergent and discriminant validity, sensitivity and reliability in a German normative population ( $n=600$ ) [25].

#### *Family relationship index*

The family relationship index (FRI) is a 27-item questionnaire consisting of three subscales of the Family Environment Scale assessing expressiveness, cohesion and conflict within a family [26, 27]. Expressiveness refers to the extent to which family members are encouraged to act openly and express feelings directly; cohesion refers to the degree of commitment, help and support family members provide for each other, and conflict refers to the amount of openly expressed anger, aggression and conflict among family members. The FRI was completed by the parents and calculated as the sum of these three subscales (after the conflict subscale had been reversed), with higher scores indicating better family relations.

#### *Childhood post-traumatic stress disorder reaction index*

The childhood post-traumatic stress disorder reaction index (CPTSD-RI) is a 20-item self-report scale designed to assess post-traumatic stress reactions of children between 6–16 years of age, following exposure to a broad range of traumatic events [28]. The scale has been found to be valid in detecting symptoms of post-traumatic stress disorder. Items are rated on a 0–4 scale. Scores are classified as mild reaction (total score 12–24), moderate (25–39), severe (40–59), and very severe ( $>60$ ) [29]. In our study, a valid German version of the CPTSD-RI was used [30].

#### *Socioeconomic status*

The socioeconomic status (SES) was calculated by means of a score reflecting paternal occupation and maternal education (range 2–12). Three social classes were defined as follows: scores 2–5 as lower class; scores 6–8 as middle class; scores 9–12 as upper class. This measure has been shown to be a reliable and valid indicator of SES in our community [31].

#### *Procedure*

The study was approved by the local Ethics Committee of the University Hospital of Zurich, and written informed consent was obtained from all parents and patients older than 10 years. All 37 children were interviewed by one paediatrician who was not involved in the patients' care and was unaware of the current graft function. Twenty-nine parents (both parents in 23 patients, only mothers in six children) returned the TACQOL-parents' form and the CBCL, filled in either during clinic in the hospital or at home.

#### *Statistical analyses*

The null hypothesis tested was that, in comparison with healthy children, children after RTPL had no impairment of QOL and psychosocial adjustment. Student's *t*-test or the Mann–Whitney *U* test, depending on data distribution, was used to compare groups. All analyses were performed with two-sided tests. To evaluate determinants of QOL and PA, we computed Spearman correlation coefficients. A value of  $P<0.05$  was considered to be significant (SPSS statistical software package, version 11.5, SPSS, Chicago, IL, USA).

## **Results**

### *Clinical evaluation*

Median age at investigation was 14.5 years (range 6.5–17 years) at a median 4.5 years (range 0.5–12.8 years) after

RTPL (Table 1). Two, 26 and nine patients were younger than 7 years, 8–15 years and 16–18 years, respectively.

Estimated glomerular filtration rate was 82 ml/min per 1.73 m<sup>2</sup> (range 32–137 ml/min per 1.73 m<sup>2</sup>), and 17 patients were on antihypertensive medication. There were no differences in the clinical data and SES between the eight children for whom the parents did not respond to the questionnaires and the patients with responding parents.

### Quality of life

The patients' self reports were normal for five out of seven dimensions (basic motor function, autonomy, cognition, social functioning and negative emotions), significantly better for physical complaints ( $P<0.0005$ ) and significantly impaired for positive emotions ( $P=0.02$ ) in comparison with those of the healthy controls (Table 2).

The parents reported normal functioning in three dimensions (physical complaints, social functioning and negative emotions), but stated four dimensions as significantly impaired (Table 2).

Agreement between child and parent ratings was high for physical dimensions and moderate for social and psychological dimensions of QOL (physical functions  $r=0.56$ ,  $P<0.0005$ ; motor functioning  $r=0.61$ ,  $P<0.0005$ ; autonomy  $r=0.41$ ,  $P=0.03$ ; cognitive functioning  $r=0.42$ ,  $P=0.03$ ; social functioning  $r=0.36$ ,  $P=0.08$ ; positive emotional functioning  $r=0.41$ ,  $P=0.04$ ; negative emotional functioning  $r=0.38$ ,  $P=0.04$ ).

### Psychosocial adjustment

Psychosocial adjustment was impaired when compared with that of healthy control children, as parents reported significantly ( $P=0.02$ ) higher rates of internalizing behavioural problems, indicating that their children experienced more social withdrawal, somatic complaints, anxiety and depressive symptoms (Table 3).

### Childhood post-traumatic stress disorder reaction index

Reliable results of the scale were obtained for 35 children. Doubtful reaction was observed for 26 (74%) of the children, whereas nine (26%) children showed mild reactions. Mean CPTSD-RI was 8.3 (standard deviation=5.2).

### Determinants of QOL

In contrast to the children's self-reports, parents reported QOL was significantly correlated with both illness-related variables and family climate (Table 4). Better functioning with regard to negative emotions was correlated with older age at examination, cadaveric organ donation and immunosuppression without steroids. Positive functioning was correlated with age at RTPL. A negative correlation was found between positive emotional functioning and younger age at RTPL. The dimensions positive emotions, physical complaints and autonomy scored not significantly differently between patients undergoing dialysis prior to RTPL and those with pre-emptive RTPL (Table 4).

Concerning the influence of family characteristics, maternal distress (GSI) showed a negative correlation with most of the TACQOL child and parent subscales, whereas paternal distress was only negatively correlated with the subscales of bodily complaints and negative emotions (Table 4).

Neither gender nor body height (assessed as standard deviation score) had a significant impact on QOL (data not shown).

### Determinants of PA and CPTSD-RI

A negative correlation was found between externalizing behavioural problems and duration of dialysis. A positive correlation was observed between the internalizing behaviour problems and steroid withdrawal. PA was significantly correlated with both maternal and paternal stress (GSI), but not with the family relationship index (FRI). Neither gender,

**Table 1** Clinical data of 37 patients. Data are given as median (range)

| Parameter   | Data                |
|---|---------------------|
| Gender: male ( <i>n</i> ; %)/female ( <i>n</i> ; %)                           | 20 (54%)/17 (46%)   |
| Age at onset of dialysis (years)  | 6.6 (0.3–14.8)      |
| Haemodialysis ( <i>n</i> )  | 16                  |
| Peritoneal dialysis ( <i>n</i> )  | 11                  |
| Duration of dialysis (months)   | 19 (2–58)           |
| Age at renal transplantation (years)  | 8.3 (2–15.2)        |
| Living-related donation ( <i>n</i> ; %)/cadaveric donation ( <i>n</i> ; %)    | 22 (59%)/15 (41%)   |
| Age at investigation (years)  | 14.5 (6.5–17.3)     |
| Follow-up since renal transplantation (years)                                 | 4.5 (0.5–12.8)      |
| Glomerular filtration rate (ml/min per 1.73 m <sup>2</sup> body surface area) | 82 (32–137)         |
| Body height (standard deviation score, SDS)                                   | −0.8 (−2.8 to +0.8) |
| Body mass index (standard deviation score, SDS)                               | +0.2 (−1.4 to +2.3) |

**Table 2** Sample means and normative data for health-related quality of life measures

| Measure (Cronbach's $\alpha$ )    | Sample |     | Normative data |     | $P^a$   |
|-----------------------------------|--------|-----|----------------|-----|---------|
|                                   | Mean   | SD  | Mean           | SD  |         |
| TACQOL children's form ( $n=37$ ) |        |     |                |     |         |
| Body (0.44)                       | 28.2   | 2.8 | 24.2           | 5.3 | <0.0005 |
| Motor (0.71)                      | 30.3   | 2.5 | 29.8           | 3.3 | 0.23    |
| Auto (0.51)                       | 31.7   | 1.0 | 31.4           | 1.7 | 0.09    |
| Cognition (0.83)                  | 28.4   | 3.4 | 28.0           | 4.1 | 0.44    |
| Social (0.66)                     | 29.9   | 2.9 | 29.4           | 3.0 | 0.33    |
| Emotion (positive) (0.70)         | 12.3   | 2.2 | 13.3           | 2.7 | 0.02    |
| Emotion (negative) (0.84)         | 12.5   | 3.1 | 11.6           | 2.6 | 0.10    |
| TACQOL parents' form ( $n=29$ )   |        |     |                |     |         |
| Body (0.76)                       | 26.4   | 4.7 | 27.6           | 3.7 | 0.18    |
| Motor (0.80)                      | 28.5   | 3.9 | 31.0           | 2.3 | 0.002   |
| Auto (0.73)                       | 30.0   | 2.7 | 31.4           | 1.6 | 0.01    |
| Cognition (0.82)                  | 26.0   | 5.4 | 29.2           | 3.7 | 0.04    |
| Social (0.84)                     | 28.1   | 4.7 | 30.0           | 2.3 | 0.05    |
| Emotion (positive) (0.85)         | 12.7   | 2.9 | 15.0           | 1.8 | <0.0005 |
| Emotion (negative) (0.69)         | 11.8   | 2.7 | 11.7           | 2.3 | 0.84    |

<sup>a</sup> *t*-Test with normative data

nor body height had a significant impact on PA (data not shown).

The severity of post-traumatic stress symptoms reaction index (CPTSD-RI) was correlated with the age at examination, but not with the age at RTPL.

**Discussion**

We report a comprehensive cross-sectional analysis on QOL and PA and their determinants in children after RTPL. The patients' self-reports of QOL were normal for the majority of dimensions, significantly better in one dimension (physical complaints) and impaired in only one dimension (positive emotions). In contrast, the parents evaluated their children's QOL and PA more pessimistically, as they rated the majority of QOL dimensions and internalizing behaviour, e.g. social withdrawal, anxiety or depressive symptoms, as significantly impaired.

Surprisingly, and in contrast to our hypothesis, patients after RTPL rated their QOL subscale physical complaints better than did healthy controls. One might speculate that this phenomenon is based on the fact that regular dialysis prior to RTPL may provide the awareness of severe physical complaints. However, our data did not show any significant correlation between the subscales physical complaints and dialysis prior to RTPL. Previous studies had shown that children and adolescents who had undergone transplantation had better physical and psychosocial health than did patients on dialysis [12, 13], but there are no

prospective studies analysing QOL in children on dialysis and after RTPL.

A few preliminary studies on adults undergoing organ transplantation have suggested that these patients rated at least some dimensions of QOL better than healthy controls did. After lung or marrow transplantation, adults reported less anxiety and depression and a higher satisfaction, and liver transplantation patients reported less depression [32]. Patients indicated an increase in happiness with life after transplantation [32, 33]. The reason for this positive psychological state after transplantation might be that patients compare their health situation after transplantation with the life-threatening illness before the transplantation, a mental procedure called "cognitive reframing" or "response shift" [33]. However, in children, prospective studies evaluating QOL before and after RTPL are needed in order to analyse potential mechanisms influencing the dimensions of QOL and their determinants. In contrast to our data, impairment of QOL after RTPL was previously described in adult patients with paediatric onset of end-stage renal failure <15 years of age. Patients achieved fewer milestones than peers with respect to autonomy and social and psychosexual development and finally displayed less risk behaviour [14]. Qvist et al. reported that overall QOL, as scored by the patients themselves, was significantly impaired in children receiving transplants <5 years [9].

In our study, parents evaluated QOL more pessimistically than the patients themselves did. These data confirmed previous observations of divergent rating between children and their parents, not only concerning chronic renal failure [10, 11], but also concerning other chronic illnesses [4–7]. Possible reasons are either that children rate their QOL too optimistically because of confounding factors such as face-to face interview or mechanisms of avoidance. On the other hand, parents may rate their children's QOL too pessimistically, because their pessimistic view might be due to an impairment of parents' (especially mothers') own QOL, reflecting shared variance between mothers' psychological strain and the rating of her child's QOL [10]. Similar observations have been made in children with

**Table 3** Sample means and normative data for psychological adjustment

| Child behaviour checklist (CBCL) ( $n=29$ ) | Sample |      | Normative data <sup>a</sup> |      | $P^b$ |
|---|--------|------|-----------------------------|------|-------|
|   | Mean   | SD   | Mean                        | SD   |       |
| CBCL-total score <sup>c</sup>               | 53.4   | 10.1 | 50.0                        | 10.0 | 0.08  |
| CBCL-internalizing score <sup>c</sup>       | 54.8   | 10.3 | 50.0                        | 10.0 | 0.02  |
| CBCL-externalizing score <sup>c</sup>       | 50.6   | 9.0  | 50.0                        | 10.0 | 0.73  |

<sup>a</sup> Normative data are from manual scale

<sup>b</sup> *t*-Test with normative data

<sup>c</sup> Total Behavioural Problem score (T-score)



**Table 4** Spearman's correlation coefficients between TACQOL and CBCL scores and illness-related variables and family climate (*CDR* cadaveric donation, *FRI* family relationship index, *GSI* global severity index)

| Variable                               | Illness-related variables |                    |                    |                   |                    |                    |                       | Family climate    |                    |                    |
|--|---------------------------|--------------------|--------------------|-------------------|--------------------|--------------------|-----------------------|-------------------|--------------------|--------------------|
|  | Age                       | Time on dialysis   | Age at RTPL        | CRD               | Steroid withdrawal | Graft function     | Dialysis <sup>d</sup> | FRI               | GSI mother         | GSI father         |
| TACQOL children's form ( <i>n</i> =37) |                           |                    |                    |                   |                    |                    |                       |                   |                    |                    |
| Body                                   | -0.09                     | -0.03              | -0.11              | 0.05              | -0.28              | -0.10              | -0.03                 | 0.21              | -0.60 <sup>c</sup> | -0.33              |
| Motor                                  | -0.13                     | 0.09               | -0.16              | 0.27              | 0.04               | -0.02              | 0.13                  | -0.02             | -0.13              | -0.12              |
| Auto                                   | 0.13                      | -0.02              | 0.14               | 0.08              | 0.15               | 0.14               | -0.03                 | -0.01             | 0.09               | 0.02               |
| Cognition                              | -0.22                     | -0.05              | 0.01               | -0.05             | 0.23               | 0.24               | -0.14                 | -0.31             | -0.07              | 0.34               |
| Social                                 | -0.06                     | 0.19               | 0.04               | 0.07              | 0.07               | 0.05               | 0.08                  | 0.11              | -0.47 <sup>b</sup> | -0.21              |
| Emotion positive                       | -0.30                     | 0.14               | -0.05              | 0.06              | 0.19               | 0.02               | -0.28                 | -0.03             | -0.11              | 0.34               |
| Emotion negative                       | -0.03                     | 0.03               | 0.02               | 0.03              | -0.01              | 0.11               | 0.03                  | 0.04              | -0.41 <sup>a</sup> | -0.25              |
| TACQOL parents' form ( <i>n</i> =29)   |                           |                    |                    |                   |                    |                    |                       |                   |                    |                    |
| Body                                   | 0.15                      | -0.05              | -0.12              | 0.14              | -0.29              | -0.37 <sup>a</sup> | -0.18                 | 0.17              | -0.61 <sup>c</sup> | -0.43 <sup>a</sup> |
| Motor                                  | 0.00                      | -0.23              | -0.23              | 0.16              | -0.34              | -0.09              | 0.10                  | 0.25              | -0.35              | -0.09              |
| Auto                                   | 0.20                      | -0.15              | -0.19              | 0.12              | -0.30              | -0.29              | 0.14                  | 0.23              | -0.40 <sup>a</sup> | -0.29              |
| Cognition                              | -0.09                     | 0.01               | -0.04              | 0.04              | -0.20              | -0.12              | 0.08                  | 0.34              | -0.46 <sup>a</sup> | 0.05               |
| Social                                 | 0.17                      | 0.27               | -0.37              | 0.38              | -0.33              | -0.34              | 0.16                  | 0.35              | -0.62 <sup>c</sup> | -0.39              |
| Emotion positive                       | 0.07                      | 0.20               | -0.41 <sup>a</sup> | 0.01              | -0.29              | -0.22              | -0.33                 | 0.30              | -0.31              | 0.14               |
| Emotion negative                       | 0.37 <sup>a</sup>         | 0.25               | -0.14              | 0.51 <sup>b</sup> | 0.44 <sup>a</sup>  | -0.27              | 0.08                  | 0.52 <sup>b</sup> | -0.54 <sup>b</sup> | -0.55 <sup>b</sup> |
| CBCL ( <i>n</i> =29)                   |                           |                    |                    |                   |                    |                    |                       |                   |                    |                    |
| Total                                  | -0.20                     | -0.12              | 0.07               | 0.30              | 0.41               | 0.22               | -0.15                 | -0.35             | 0.56 <sup>b</sup>  | 0.43 <sup>a</sup>  |
| Internalizing                          | -0.14                     | -0.01              | 0.11               | 0.28              | 0.57 <sup>b</sup>  | 0.24               | -0.02                 | -0.38             | 0.47 <sup>a</sup>  | 0.32               |
| Externalizing                          | -0.13                     | -0.48 <sup>a</sup> | 0.06               | 0.35              | 0.28               | 0.07               | -0.37                 | -0.20             | 0.55 <sup>b</sup>  | 0.48 <sup>a</sup>  |
| CPTSD-RI ( <i>n</i> =29)               | 0.42 <sup>a</sup>         | 0.05               | 0.10               | 0.05              | 0.15               | -0.05              | 0.30                  | -0.03             | 0.14               | 0.07               |

<sup>a</sup> *P*<0.05<sup>b</sup> *P*<0.01<sup>c</sup> *P*<0.001<sup>d</sup> Determinant without significant correlation

steroid-sensitive nephrotic syndrome [4], where parents evaluated their children's QOL more pessimistically than the children themselves did. Another reason for the divergence in the perception of QOL may reflect differing parental awareness concerning the impact of their children's disease, particularly on emotions, pain and long-term outcome. Furthermore, it may be assumed that the constant fear of parents that their children might suffer an acute rejection episode, lose the graft and, finally, face the burden of restarting dialysis creates a more pessimistic statement of their children's QOL.

With regard to PA after RTPL, mothers' reports of impaired internalizing behaviour indicated that their children were at risk of psychological disorders, in particular that patients experienced more social withdrawal, somatic complaints, and anxiety and depressive symptoms [15]. Our study results were in line with those of previous reports indicating impairment of emotional and psychosocial adaptation in patients with ESRF [15, 16] and after RTPL [9]. Even after successful RTPL, the burden of a chronic disease remains, based on continuing and lifelong dependence on regular and consistent medical treatment. There-

fore, not only is discipline and rationality required from a very early age, but also there is the ongoing perception of being different from healthy peers. As the daily caregivers and educators of their children, mothers are continuously confronted with the concern about their children's health and the complexity of the navigation to adulthood.

With regard to illness-related determinants of QOL and PA, long duration of dialysis negatively affected externalizing behaviour, indicating more social problems. Dialysis and its consequences imply less autonomy, and, therefore, withdrawal of social contacts, especially with the adolescents' peers.

Young age at RTPL was associated with more post-traumatic stress symptoms and impaired negative emotions than was older age. This age-related difference might be explained by the fact that older children understand the treatment procedures better and, therefore, might cope better with their disease [34]. In contrast to the patients after RTPL, in paediatric burn survivors younger age was a significant predictor of good QOL [5]. However, our observation may underline the importance that paediatric nephrologists have repeatedly to give adequate information and explanations not only to the parents, but also to the children.

Parents reported a better coping with the child's negative emotion after cadaveric RTPL than after living-related RTPL. Donor ability plays an important role in anxiety and depression among renal transplantation candidates and potential living-related organ donors. In the case of living-related donation by one of the parents, the "non-donor parents" seemed to constitute a psychological risk group, including more anxiety and stress with special need for psychological support [35]. Cadaveric donation in paediatric RTPL as a determinant of QOL and PA has, so far, not been examined.

In our patients, steroid-free immunosuppression was associated with a positive impact on patients' negative emotions and led to fewer internalizing behavioural problems than in patients on steroids. Our results confirmed similar findings in other patients' groups treated with steroids, such as asthma [36], haematological malignancies [37] or steroid-sensitive nephrotic syndrome [4]. Whether factors other than steroids influenced our findings remains an open question. However, for the optimization of QOL and PA, it is suggested that steroids be avoided in long-term immunosuppression [18, 38].

Our data revealed that, within psychosocial variables, good family climate and increased level of global emotional distress in mothers had an important impact on both QOL and PA. There seemed to be a shared variance between children's QOL and PA and the mothers psychological distress [4, 10]. A good family climate was protective for positive adjustment, not only in healthy populations, but also for those with chronic disorders [4–6]. Moreover, higher family cohesion also resulted in fewer hospitalizations of patients with kidney disease [17].

This single-centre, cross-sectional study represents only a small group of children after RTPL. Patients were interviewed, on average, 4.5 years after RTPL, and the majority of patients had good graft function. Yet, the application of standardized tests in both self-rating and foreign-rating forms allows validation of the assessment of QOL and PA and its determinants. However, limitations of the present study [e.g. the small number of patients, wide range of ages, high number of correlations, low internal consistencies of two TACQOL-child form (CF) scales] should be taken into consideration, and they underline the fact that, in future, more studies evaluating QOL and PA will be due. Additionally, the controls in the TACQOL-parent form (PF) were younger than our patients; however, as negative emotions is the only correlating scale, this limitation seems to be acceptable.

In conclusion, children with a functioning renal graft rated some QOL dimensions higher than did healthy controls and evaluated their QOL and PA more optimistically than did their parents. Both illness-related variables and family environment were important determinants.

**Acknowledgement** The study was supported by the Foundation Mercator Switzerland.

## References

- McDonald SP, Craig JC (2004) Long-term survival of children with end-stage renal disease. *N Engl J Med* 350:2654–2662
- Seikaly MG, Ho PL, Emmett L, Fine RN, Tejani A (2003) Chronic renal insufficiency in children: the 2001 Annual Report of the NAPRTCS. *Pediatr Nephrol* 18:796–804
- Groothoff JW (2005) Long-term outcomes of children with end-stage renal disease. *Pediatr Nephrol* 20:849–853
- Ruth EM, Landolt MA, Neuhaus TJ, Kemper MJ (2004) Health-related quality of life and psychosocial adjustment in steroid-sensitive nephrotic syndrome. *J Pediatr* 145:778–783
- Landolt MA, Grubenmann S, Meuli M (2002) Family impact greatest: predictors of quality of life and psychological adjustment in pediatric burn survivors. *J Trauma* 53:1146–1151
- Landolt MA, Nuoffer JM, Steinmann B, Superti-Furga A (2002) Quality of life and psychologic adjustment in children and adolescents with early treated phenylketonuria can be normal. *J Pediatr* 140:516–521
- Norby U, Nordholm L, Andersson-Gare B, Fasth A (2006) Health-related quality of life in children diagnosed with asthma, diabetes, juvenile chronic arthritis or short stature. *Acta Paediatr* 95:450–456
- Fadowski J, Cole SR, Hwang W, Fiorenza J, Weiss RA, Gerson A, Furth SL (2006) Changes in physical and psychosocial functioning among adolescents with chronic kidney disease. *Pediatr Nephrol* 21:394–399
- Qvist E, Narhi V, Apajasalo M, Ronnholm K, Jalanko H, Almqvist F, Holmberg C (2004) Psychosocial adjustment and quality of life after renal transplantation in early childhood. *Pediatr Transplant* 8:120–125
- Manificat S, Dazard A, Cochat P, Morin D, Plainguet F, Debray D (2003) Quality of life of children and adolescents after kidney or liver transplantation: child, parents and caregiver's point of view. *Pediatr Transplant* 7:228–235
- Olausson B, Hansson S, Wennerstrom M, Olausson M, Friman S (2001) Quality of life after paediatric kidney transplantation: a single-centre experience. *Transplant Proc* 33:2446–2448
- Hasegawa A, Oshima S, Takahashi K, Uchida K, Ito K, Sonoda T (2005) Improvement of quality of life in tacrolimus-based pediatric renal transplant recipients and their caregivers, including donors. *Transplant Proc* 37:1771–1773
- Goldstein SL, Graham N, Burwinkle T, Warady B, Farrah R, Varni JW (2006) Health-related quality of life in pediatric patients with ESRD. *Pediatr Nephrol* 21:846–850
- Grootenhuys MA, Stam H, Last BF, Groothoff JW (2006) The impact of delayed development on the quality of life of adults with end-stage renal disease since childhood. *Pediatr Nephrol* 21:538–544
- Madden SJ, Hastings RP, V'ant Hoff W (2002) Psychological adjustment in children with end stage renal disease: the impact of maternal stress and coping. *Child Care Health Dev* 28:323–330
- Karrfelt HM, Lindblad FI, Crafoord J, Berg UB (2003) Renal transplantation: long-term adaptation and the children's own reflections. *Pediatr Transplant* 7:69–75
- Soliday E, Kool E, Lande MB (2001) Family environment, child behavior, and medical indicators in children with kidney disease. *Child Psychiatry Hum Dev* 31:279–295
- Laube GF, Falger J, Kemper MJ, Zingg-Schenk A, Neuhaus TJ (2007) Selective late steroid withdrawal after renal transplantation. *Pediatr Nephrol* 22:1947–1952

19. Schwartz GJ, Haycock GB, Edelmann CM Jr, Spitzer A (1976) A simple estimate of glomerular filtration rate in children derived from body length and plasma creatinine. *Pediatrics* 58: 259–263
20. Vogels T, Verrips GHW, Koopman HM, Theunissen HCM, Fekkes M, Kamphuis RP (2000) TACQOL manual, parent form and child form. Leiden Centre for Child Health and Pediatrics LUMC-TNO
21. Vogels T, Verrips GH, Verloove-Vanhorick SP, Fekkes M, Kamphuis RP, Koopman HM, Theunissen NC, Wit JM (1998) Measuring health-related quality of life in children: the development of the TACQOL parent form. *Qual Life Res* 7:457–465
22. Achenbach T (1991) Manual for child behavior checklist/4–18. University of Vermont, Burlington
23. Doepfner M, Melchers P, Fegert J (1994) Deutschsprachige Konsensusversionen der Child Behavior Checklist (CBCL 4–18), der Teacher Report Form (TRF) und der Youth Self Report Form (YSR). *Kindheit Entwicklung* 3:54–59
24. Derogatis LR, Lazarus L (1994) SCL-90-R, Brief Symptom Inventory, and matching clinical rating scales. In: Maruish ME (ed) *The use of psychological testing for treatment planning and outcome assessment*. Lawrence Erlbaum Associates, Hillsdale, NJ, pp 217–224
25. Franke GH (1997) First studies about the psychometric quality of the Brief Symptom Inventory (BSI). *Z Med Psychol* 6:159
26. Moos RH, Moos BS (1994) Family environment scale manual: development, applications, research. Consulting Psychologist Press, Palo Alto, CA
27. Schneewind KA, Beckmann M, Hecht-Jackl A (1985) Das familiendiagnostische Testsystem. Universität, Institut für Psychologie, München
28. Frederick CJ (1985) Selected foci in the spectrum of post-traumatic stress disorder. In: Laube J, Murphy SA (eds) *Perspectives on disaster recovery*. Appleton-Century-Crofts, Norwalk, CN, pp 110–130
29. Goenjian AK, Pynoos RS, Steinberg AM, Najarian LM, Asarnow JR, Karayan I, Ghurabi M, Fairbanks LA (1995) Psychiatric comorbidity in children after the 1988 earthquake in Armenia. *J Am Acad Child Adolesc Psychiatry* 34:1174–1184
30. Landolt MA, Vollrath M, Timm K, Gnehm HE, Sennhauser FH (2005) Predicting posttraumatic stress symptoms in children after road traffic accidents. *J Am Acad Child Adolesc Psychiatry* 44:1276–1283
31. Largo RH, Pfister D, Molinari L, Kundu S, Lipp A, Duc G (1989) Significance of prenatal, perinatal and postnatal factors in the development of AGA preterm infants at five to seven years. *Dev Med Child Neurol* 31:440–456
32. Goetzmann L, Klaghofer R, Wagner-Huber R, Halter J, Boehler A, Muellhaupt B, Schanz U, Buddeberg C (2007) Quality of life and psychosocial situation before and after a lung, liver or an allogeneic bone marrow transplant. Results from a prospective study. *Swiss Med Wkly* 137 [Suppl 155]:115S–124S
33. Limbos MM, Joyce DP, Chan CK, Kesten S (2000) Psychological functioning and quality of life in lung transplant candidates and recipients. *Chest* 118:408–416
34. Sallfors C, Hallberg LR, Fasth A (2003) Gender and age differences in pain, coping and health status among children with chronic arthritis. *Clin Exp Rheumatol* 21:785–793
35. Karrfelt HM, Berg UB, Lindblad FI, Tyden GE (1998) To be or not to be a living donor: questionnaire to parents of children who have undergone renal transplantation. *Transplantation* 65:915–918
36. Bender BG, Lerner JA, Poland JE (1991) Association between corticosteroids and psychologic change in hospitalized asthmatic children. *Ann Allergy* 66:414–419
37. Harris JC, Carel CA, Rosenberg LA, Joshi P, Leventhal BG (1986) Intermittent high dose corticosteroid treatment in childhood cancer: behavioral and emotional consequences. *J Am Acad Child Psychiatry* 25:120–124
38. Hocker B, John U, Plank C, Wuhl E, Weber LT, Misselwitz J, Rascher W, Mehls O, Tonshoff B (2004) Successful withdrawal of steroids in pediatric renal transplant recipients receiving cyclosporine A and mycophenolate mofetil treatment: results after four years. *Transplantation* 78:228–234