Quality of life and social characteristics of young adults in chronic hemodialysis with pediatric-onset renal disease

Jorge R. Ferraris^{1,2} , Rosario Luxardo³ , Alfredo M. Eymann^{2,4} , Martina Turano⁵ , Soledad Crucelegui³ , Guillermo Rosa-Diez³

ABSTRACT

Introduction. Health-related quality of life (HRQL) and its social consequences have not been evaluated in adults who started renal replacement therapy (RRT) in childhood/adolescence and are currently on hemodialysis.

Population and methods. We compared 26 patients who started their RRT at <18 years with a group that started their RRT at 18 years or more. We studied social variables and HRQL with the KDQOL-36 questionnaire. Scores >50 indicate good HRQL.

Results. The study was conducted in 2018. The scores were: physical health: 55 and 58.1; mental health: 61.2 and 66.7; disease burden: 39.2 and 37.3; symptoms and problems: 75.6 and 78.5; effects: 65.9 and 51.6 (p < 0.019) for those who started RRT at pediatric age or adult age respectively. Socioeconomic status and education were similar in both groups. Fifty percent of the patients with RRT from pediatric age and 38.5% of those who started with RRT in adulthood were unemployed. In the group who started RRT at pediatric age, 61.5% lived with their parents vs. 19% of those who started RRT in adulthood; 11.5% of the patients with RRT at pediatric age had a partner vs. 42.3% of those who started RRT as adults.

Conclusions. Adults with the onset of RRT in childhood who are currently on hemodialysis have a good perception of HRQL, superior to adults with a recent onset of RRT. They have a good education, but their lack of work, independent living, and having a partner is related to the burden of illness.

Keywords: quality of life; renal replacement therapy; chronic renal failure; interpersonal relationships; questionnaire KDQOL-36.

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¹ Pediatric Nephrology Service, Hospital Italiano de Buenos Aires, City of Buenos Aires, Argentina; ² Universidad de Buenos Aires, City of Buenos Aires, Argentina; ³ Adult Nephrology Service, Hospital Italiano de Buenos Aires, City of Buenos Aires, Argentina; ⁴ Pediatric Clinic Service, Hospital Italiano de Buenos Aires, City of Buenos Aires,

Correspondence to Jorge R. Ferraris: jorge.ferraris@hospitalitaliano.org.ar

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INTRODUCTION

The generations of adults with chronic disease from childhood and adolescence who survive is a new frontier in health care, which is why attention should be paid to their health-related quality of life (HRQL).^{1,2} Renal terminal chronic disease (RTCD) has an estimated annual growth of 4% worldwide.^{3,4}

The adult population with RTCD consists of patients who started treatment as adults and those who started renal replacement therapy (RRT) at pediatric age and continued it as adults.

Dialysis is time-consuming, with complications, including after kidney transplantation, that alter the daily functioning of these patients.⁵ In addition, graft loss is a common cause of RTCD, representing 5% of dialysis patients, and alters HRQL.⁶

The World Health Organization defines HRQL as an individual's perception of where they exist in the context of their culture, the value system in which they live, and their expectations, norms, and concerns.^{7,8}

The impact of RTCD in childhood and throughout life has yet to be well studied.^{9,10} HRQL and its social consequences have not been evaluated in young adults who started RRT as children and adolescents and continue dialysis treatment today.

The objectives were to study HRQL, socioeconomic status, education, employment, couples, children, and housing in adults who started their RRT at pediatric age and are currently on chronic hemodialysis and to compare them with patients who started their RRT as adults and on national standards.

POPULATION AND METHODS

A cross-sectional study on chronic hemodialysis in adult patients with RTCD was conducted in 2018. We included patients who started their RRT at <18 years old and who were on hemodialysis for more than one year. They were compared with a 1:1 control group of chronic hemodialysis patients who started their RRT at \geq 18. These patients had a chronological age and sex equal to the group to be investigated. We studied clinical, biochemical, and social variables.

HRQL was studied with the Kidney Disease Quality of Life questionnaire (KDQOL-36), available in Spanish at www.rand.org. It has been validated in Spanish¹¹⁻¹³ and in Argentina.¹⁴ It has two components: a general component with 12 questions and a specific component with 24 questions related to kidney disease. The components are as follows: physical component summary (questions 1-5, PH) investigates physical health; summary of the mental component (questions 6-12, MH) inquires into mental health; disease burden (questions 13-16, burden) considers the extent to which the disease interferes with the patient's life; symptoms and problems (questions 17-28, SP), how the complications and symptoms of the disease upset the patient; and effects of the disease (questions 29-36, effects) consider whether the disease affects different areas: diet. sexual life, physical appearance, travel, among others. The scores of items have a value from 0 to 100, where 0 indicates the worst quality of life, and 100 is the best quality of life. The benchmark is 50; lower scores correspond to a regular or poor quality of life, and 51 or more represents a good quality of life.

The questionnaire was answered anonymously, placed in a mailbox, and then analyzed using the Microsoft Excel template available on the official KDQOL website. All patients answered the questionnaire.

Socioeconomic status was divided into three categories: low <1000 dollars/month, middle 1000-2000 dollars/month, and high >2000 dollars/ month. Investigation into whether they lived alone, with their parents or in a couple, with or without children; whether they had rented occupation; and whether they had primary, secondary, and university education. The responses were compared between groups and with data from the general population of Argentina (Centro de Estudios de la Educación Argentina of the Universidad de Belgrano, Universidad Católica Argentina, Instituto Nacional de Estadística y Censos de la República Argentina, and Universidad Torcuato Di Tella).

Our institution's Ethics Committee approved the study. Patients were asked for informed consent.

Statistical analysis

Results were expressed as mean standard deviation (SD) or percentages. The Student t-test and chi-square test were used to determine group differences. The Pearson correlation coefficient was used to calculate correlations between the variables. The consistency of the questionnaire was evaluated using Cronbach's alpha coefficient. A *p*-value of <0.05 was considered significant.

RESULTS

A total of 52 patients (31 women) were analyzed, 26 of whom started RRT at pediatric age (RTCD before 18 years old) and 26 started RRT as adults (RTCD after 18 years). All were on chronic hemodialysis.

Table 1 shows the clinical variables. The current age, sex, and time on hemodialysis were not different in both groups since these three variables correspond to the inclusion criterion of the group with RTCD beginning in adulthood. The rest of the variables were distinct in both groups.

Etiologies, co-morbidities, and biochemical variables are shown in *Table 2*. The variables were not different.

The scores of the KDQOL-36 domains were calculated according to the individual responses of each item (Table 3). Comparing the total scores of the two groups, no differences were found: $63.9 \pm 18.0 \text{ vs.} 62.8 \pm 16.6$. When the domains were analyzed separately, it was observed (*Figure 1*) that the score was higher than 50 points in all domains except the burden domain; domain S/P had the highest score, and the domain of the effects was perceived as a better HRQL in the group that started RTCD at pediatric age. Studying each question, these patients were found to have better HRQL regarding the RTCD start group in adulthood for hydration, working capacity, and travel (questions 29, 31, 32).

On a scale of 1 to 100, 68% and 69% of the PH domain scores, 71% and 70% of the MH domain scores, and 79.4% and 60.8% of the domain effects were greater than 50, indicating a good perception of HRQL for both groups. The

percentages of the burden domain were 43% and 37,2% for those who started the RRT in childhood or adulthood.

We highlight two questions: Question 1 asks how they perceive their health; 63% and 69% said it was good or very good. Question 36 investigates how the disease affects physical and personal appearance (weight, height, body mass index); 81% and 77% of patients with the onset of RRT in pediatric or adult age were not upset or slightly upset.

The five domains of both groups had a positive correlation (*Table 4*).

Internal consistency showed adequate values for the KDQOL-36 questions for the groups (0.937 and 0.925).

Table 5 shows the socioeconomic level, education, work, housing, couple, and children according to the beginning of the RRT. These variables are compared with those of the general population.

In both groups, the socioeconomic and educational levels were similar to those of the general population. Fifty percent of patients with onset of RRT at pediatric age and 38.5% of patients who started RRT in adulthood were unemployed. This contrasts with the overall unemployment of 9.2%.⁵ 61.5% of patients who started RRT at pediatric age lived with their parents, a different percentage from the group with RTCD from adulthood and the general population. In patients with a pediatric-onset RTCD, there was an inverse correlation between the time spent on a kidney transplant and the time spent living with their parents (r 0.4, *p* <0.043).

TABLE 1. Comparison o	of clinical variables	according to the age o	of onset of terminal chronic disease
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Variable	RCTD <18 years	RCTD ≥18 years	р
Current age (years)	32.0 ± 7.0	35.0 ± 9.0	NS
Sex (F/M)	17/9	14/12	NS
Hemodialysis time (years) (current)	4.7 ± 2.0	3.8 ± 3.0	NS
Age of onset (years)	10.1 ± 5.0	28.9 ± 7.1	<0.005
RRT time (years)	21.8 ± 8.0	8.8 ± 5.9	<0.005
Time since transplant (years)	11.7 6.8 (32 Tx)*	7.7 5.2 (11 Tx)**	<0.001
Dialysis time (HD+PD) (years)	10.1 ± 5.1	5.6 ± 3.3	<0.005
BMI, kg/H ²	21.0 ± 4.2	24.9 ± 4.4	<0.005
SD weight	-0.85 ± 0.17	1.17 ± 2.1	<0.005
SD height	-1.95 ± 0.38	-0.22 ± 1.43	<0.005

* 20 patients 1 Tx/each, 6 patients 2 Tx/each.

** 8 patients 1 Tx/each, 1 patient 3 Tx/each.

Tx: kidney transplantation; RCTD: renal chronic terminal disease; RRT: renal replacement therapy; HD: hemodialysis; PD: peritoneal dialysis; BMI: body mass index; NS: not significant; SD: standard deviation.

	RCTD <18 years	RCTD ≥18 years	p
	n/%	n/%	
Etiology			
Uropathy/renal dysplasia	8/30.8	3/11.5	NS
Typical UHS	5/19.2	4/15.4	NS
FSGS	4/15.4	4/15.4	NS
Genetic	4/15.4	1/3.8	NS
IgA-IgG nephropathy	1/3.8	5/19.2	NS
Diabetes 1	-	2/7.7	-
Other	4/15.4	7/26.9	NS
Comorbidities			
Hyperparathyroidism	21/80.7	22/84.6	NS
Partial parathyroidectomy	12/46.1	12/46.1	NS
Arterial hypertension	13/50.0	17/65.3	NS
Dislipidemia	5/19.2	5/19.2	NS
Diabetes 2	2/7.7	2/7.7	NS
Heart disease/valve disease	6/23.1	3/11.5	NS
Peripheral vascular disease	2/7.7	2/7.7	NS
Thromboembolism	2/7.7	2/7.7	NS
Cancer	5/19.2	5/19.2	NS
Biochemical variables			
Hemoglobin (g/dl)	11.3 ± 1.7	11.3 ± 1.4	NS
Hematocrit (%)	33.5 ± 5.0	33.7 ± 4.3	NS
CRP (mg/dl)	9.6 ± 18.6	14.8 ± 32.8	NS
Albumin (g/dl)	4.4 ± 0.6	4.4 ± 0.5	NS
Calcium (mg/dl)	8.6 ± 0.8	8.9 ± 0.9	NS
Phosphorus (mg/dl)	5.2 ± 1.5	5.6 ± 1.8	NS
PTHi (pg/ml)	841.1 ± 724.6	679 ± 574.1	NS
BUN (mg/dl)	62.6 ± 11.0	65.8 ± 15.3	NS
Creatinine (mg/dl)	9.3 ± 1.3	9.6 ± 1.45	NS

TABLE 2. Etiology of terminal chronic disease, co-morbidities and biochemical variables according to groups: RCTD <18 years and RCTD ≥18 years

RCTD: terminal chronic disease; UHS: hemolytic uremic syndrome; FSGS: focal and segmental glomerulosclerosis; CRP: C-reactive protein; PTHi: intact parathyroid hormone; BUN: blood urea nitrogen; NS: not significant.

Of those patients with onset of RTCD at pediatric age, 11.6% lived in a couple and had children vs. 42.3% of those who started RTCD in adulthood, similar to the general population.

DISCUSSION

This study shows that adult patients with a history of RTCD at pediatric age, currently on chronic hemodialysis after a long period of RRT, have a good or very good perception of their HRQL. While the burden of illness interferes with their life and family, the effects were felt less strongly on their ability to work, travel, and drink. They had a good education, are unemployed, continue living with their parents, and have formed few couples with few children. Adults with newly started RTCD have a better perception of their HRQL. The disease burden interferes with their life, but the effects are more significant in the group with RTCD from the pediatric age. They had adequate education and were frequently unemployed. Most of them lived independently, as a couple, and with children.

The HRQL of adult patients with dialysistreated RTCD is lower than that of the general population.^{15,16}

Patients starting at pediatric age have a long history of RRT changes, and the loss of graft that comes with dialysis re-entry makes their lives profoundly altered. Our results indicate that a low percentage of patients scored below the benchmark value of 50, except in the burden domain, which suggests good HRQL, in contrast to adult research in chronic dialysis.^{17,18}

To our surprise, when patients with RTCD start at pediatric age, and those beginning in adulthood answered the questions of the PH and MH domains, the averages were not different.

Doma	in Questions		% of responses <50 points (benchmark score)				RCTD <18 years	RCTD ≥18 years	
		(D6 RC ⁻ <18 y	TD	RCTD		р	Mean ± SD	Mean ± SD	p
0.5				-			F4 0 + 20 4	40.4 + 04.0	
SF	1. How is your health?	(32.2)	38	(30.8)	31	ns	51.0 ± 32.1	48.1 ± 21.8	ns
	2. Does your health limit you to productive activities?		8		4 12	ns	76.9 ± 31.7	80.8 ± 28.0	ns
	3. Does your health limit you to climb several steps?		19			ns	56.0 ± 35.6	73.1 ± 34.6	ns
	4. Have you been able to do less for your health?		50 46		69 38	ns	48.1 ± 49.0	28.0 ± 44.9	ns
SM	5. Have you had limitations in your work?	002 (20 E)	40 54	(20.5)	38	ns	50.0 ± 49.0 44.2 ± 48.7	61.5 ± 48.7 61.5 ± 48.7	ns
3111	6. Because of an emotional problem, did you manage to do les	SS? (20.5)	54	(29.5)	30	ns	44.2 ± 40.7	01.3 ± 40.7	ns
	7. Because of an emotional problem. have you been		27		15		70.0 ± 44.7	84.6 ± 36.1	-
	less careful in your activities?)	27 12		23	ns	70.0 ± 44.7 74.0 ± 26.4	68.3 ± 29.9	ns
	8. How much pain has made your normal work difficult?		38		23 35	ns	74.0 ± 20.4 59.6 ± 32.2	60.3 ± 29.9 60.8 ± 27.4	ns
	9. Have you felt calm and quiet?		აი 38		35 42	ns	59.6 ± 32.2 62.8 ± 28.8		ns
	10. Did you feel a lot of energy?		30 27		42 35	ns	62.8 ± 20.0 62.8 ± 31.9	61.5 ± 27.1 63.1 ± 31.7	ns
	11. Have you felt sad and discouraged?		21		30	ns	02.0 ± 31.9	03.1±31.7	ns
	12. Have your physical health or emotional problems		4		19		67.3 ± 23.8	67.3 ± 31.6	
Durde	hampered your social activities?	(56.75)		(62.2)	81	ns	67.3 ± 23.0 33.7 ± 36.7	67.3 ± 31.6 25.0 ± 27.7	ns
Durue	n13. My kidney disease interferes with my life	(50.75)	65 73	(62.2)	88	ns			ns
	14. My kidney disease takes up too much time	EA	13	20	88	ns	26.0 ± 32.0	22.1 ± 23.3	ns
	15. I feel frustrated in dealing with my kidney disease	54	35	38	42	ns	44.2 ± 38.8	50.0 ± 36.7	ns
C/D	16. I feel a burden on my family	(9.66)		(0.66)		ns	53.8 ± 40.2	51.9 ± 37.9	ns
S/P	17. Do you feel muscle pain?	(8.66)	19	(9.66)	12 4	ns	67.0 ± 31.4	66.3 ± 28.5	ns
	18. Do you feel chest pain?		0 12		4 12	ns	92.0 ± 15.4	91.3 ± 19.5	ns
	19. Do you have cramps?					ns	73.1 ± 25.9	77.9 ± 26.2	ns
	20. Do you have itchy skin?		15		23	ns	77.0 ± 31.6	68.3 ± 32.9	ns
	21. Do you have skin dryness?		15 4		15 4	ns	74.0 ± 32.8 87.0 ± 22.5	72.1 ± 32.0 87.5 ± 19.9	ns
	22. Do you feel shortness of breath?		4			ns			ns
	23. Do you experience fainting or dizziness?		8		0 4	ns	86.5 ± 19.1	86.5 ± 18.6	ns
	24. Do you have a lack of appetite?				4 19	ns	82.0 ± 26.9	81.7 ± 21.4	ns
	25. Do you feel exhausted. without strength?		15			ns	64.0 ± 27.5	64.4 ± 29.6	ns
	26. Do you have numbress (tingling) of hands or feet?		4		15 4	ns	85.0 ± 21.2	82.7 ± 32.4	ns
	27. Do you have nausea or stomach discomfort?		8 4		4	ns	78.8 ± 29.2 85.2 ± 23.4	82.7 ± 21.7 88.5 ± 19.1	ns
Effort	28. Do you have problems with vascular access?	(20.6)		(11)		ns 0.01	53.2 ± 23.4 53.8 ± 30.0	28.8 ± 27.5	ns 0.003
Ellect	\$ 29. Do you have a restriction on liquids? 30. Do you have dietary limitations?	(20.6)	38 23	(41)	73 38	ns	55.8 ± 50.0 57.0 ± 26.9	20.0 ± 27.5 50.0 ± 28.6	ns
	31. Are you able to work at home?		23 8		30 40	0.05	57.0 ± 20.9 81.7 ± 24.6	50.0 ± 28.0 63.0 ± 34.7	0.034
	32. Are you able to travel?33. Does it affect you to depend on dectors and		31		73	0.001	59.0 ± 36.7	21.9 ± 30.9	0.001
	33. Does it affect you to depend on doctors and		23		27	20	66.0 ± 37.3	57.7 ± 34.5	20
	other health personnel?		23		21	ns	00.0 ± 37.3	57.7 ± 54.5	ns
	34. Because of your kidney disease. do you have		45		20		60.0 + 24.0		
	nervous tension or worries?		15		38	ns	69.0 ± 31.8	55.8 ± 36.2	ns
	35. Does your kidney disease affect your sex life?		8		15	ns	88.5 ± 23.9	75.0 ± 30.2	ns
	36. Does your kidney disease affect your physical appear	ance?	19		23	ns	71.0 ± 33.7	64.4 ± 35.5	ns

TABLE 3. Percentage of each item (below baseline score 50) and mean ED of the KDQOL-36 patients according to age of onset of terminal chronic disease

KDQOL-36: Kidney Disease Quality of Life; DE: desviación estándar; ERCT: enfermedad crónica terminal; SF: salud física; SM: salud mental; S/P: síntomas y problemas; ns: no significativo.

The percentage of responses from both groups that show a poor perception of HRQL, despite long-term RRT in the pediatric-age start-up RTCD group, was similar to the percentages of physical health (35.6%) and mental health (29%) of the general population. The good perception of HRQL regarding PH and MH would be related to the patient's adaptability and family support (parents in one group and their partners and children in the other).^{19,20} The difference with other publications is that treatments are now combined (better quality of dialysis), which improved patients' perception of HRQL.^{21,22}

For both groups, the symptom and effect domains had responses that suggest a good perception of HRQL. The scores of the effect

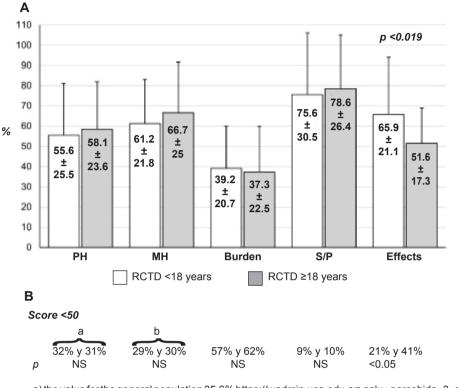


FIGURE 1. A) Distribution of KDQOL-36 scores by domains, B) Percentages of responses below the baseline (50)

a) the value for the general population 35.6% https://wadmin.uca.edu.ar>salu_percebida_3_sept (2015)

b) the value for the general population 29% https://apsa.org.ar>docs>vertx142(2018)

RCTD: terminal chronic disease; PH: physical health; MH: mental health; S/P: symptoms and problems; NS: not significant.

domain were higher in the group with RTCD beginning in the pediatric age, indicating greater resilience after a long period of living with the disease.^{23,24} Resilience expresses the ability to react positively despite difficulties, transforming

them into opportunities for growth.25

The low scores of the burden domain of kidney disease in both groups of patients can be explained because this domain evaluates the perception of frustration and the interference

TABLE 4. Correlation	s of the five domains	in the <18 years and ≥18	years groups
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Domain		Р	н	N	н	Bur	den	S	/P	Effe	ects
		RCTD <18 y	RCTD ≥18 y								
PH	Pearson correlation	1	1 0.001	0.756 0.001	0.815 0.001	0.633 0.001	0.425 0.021	0.659 0.001	0.656 0.001	0.568 0.001	0.705 0.001
МН	Pearson correlation	0.756 0.001	0.815 0.001	1	1	0.615 0.001	0.561 0.002	0.769 0.001	0.804 0.001	0.716 0.001	0.751 0.001
Burden	Pearson correlation	0.633 0.001	0.425 0.021	0.615 0.001	0.561 0.002	1	1	0.636 0.001	0.586 0.001	0.664 0.001	0.606 0.001
S/P	Pearson correlation p	0.659 0.001	0.656 0.001	0.769 0.001	0.804 0.001	0.636 0.001	0.586 0.001	1	1	0.904 0.001	0.753 0.001
Effects	Pearson correlation <i>p</i>	0.568 0.001	0.705 0.001	0.716 0.001	0.751 0.001	0.664 0.001	0.606 0.001	0.904 0.001	0.753 0.001	1	1

RCTD: terminal chronic disease; PH: physical health; MH: mental health; S/P: symptoms and problems.

	RCTD <18 years	RCTD ≥18 years	p	Reference
	n/%	n/%		(%. year 2018
Socio-economic status				
Low	3/11.5	4/15.4	NS	31.0****
Medium	3/11.5	20/77	NS	64.0
High	20/77	4/15.4	NS	5.0
Education				
Primary	7/26.9	4/15.4	NS	14 *
Secondary	13/50	17/65.4	NS	23 *
Tertiary/university	6/23	5/19.2	NS	42 *
Employment				
Employed	13/50	16/61.5	NS	62 **
Unemployed	13/50	10/38.5	NS	9.0 **
Dwelling				
Alone	3/11.5	4/15.4	NS	14 ***
With relatives	16/61.5	5/19.2	<0.001	26 ***
Couple/married				
With children	3a/11.6	11b/42.3	<0.01	45 ***
Without children	4/15.4	7/26.9	NS	15 ***

TABLE 5. Socio-economic, educational, work and housing variables according to the age of initiation of renal replacement therapy. They are compared with equal variables of the population in Argentina (reference)

* CEAUB. Centro de Estudios de la Educación Argentina, University of Belgrano. February 2023. Year 12. #118.

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*** UCA Digital Library. The Argentines and the family. ODSA. UCA, 2014.

**** www.indec.gob.ar >uploads. Technical reports. Vol 2. No 12 (1918). Consultant w on EPH-level database socio-economic of Saimo/CEIM-Martin Rosada UTDT.

a: 2 males, 1 female (1 child/each).

b: 7 males had 8 children (1 of them had 2 children) and 3 females 1 child/each.

RCTD: terminal chronic disease; NS: not significant.

of the disease in each person, regardless of symptoms or adaptation to effects in everyday life.²⁶

Positive correlations between domains suggest that increasing the positive perception of each individually or collectively could improve the perception of the disease's burden.

Interesting answers were found to question 36 on whether they are bothered by their appearance. Seventy-five percent in each group responded that they were not upset or slightly upset. This suggests that low stature or overweight of patients with disease onset in pediatric or adult age is not important. This contrasts with a study that suggested that the normal final size in patients with RTCD from childhood was positively correlated with gainful activity, education, independent living, and couples.²⁷

Another unanticipated observation was that the biochemical indicators are usually worse in patients who return to dialysis after graft loss, especially in patients with RTCD onset at pediatric age. However, these indicators were similar in patients who started RTCD before or after 18 years.⁶ The high frequency of parathyroidectomy subtotal that improves these variables could explain these findings.^{28,29}

The level of education of patients with pediatric-onset RTCD was similar to that of the general population and similar to those who started RTCD in adulthood. This is consistent with the results in the literature,³⁰ but not with other studies.^{5,9,31} Education is related to the families of patients with pediatric RTCD initiation who provide support and containment and those with a medium-high socioeconomic status. Evidence indicates that socioeconomic inequalities impact patients' health, education, and vocations.³²

Unemployment was high in patients with RTCD onset at pediatric age and adulthood, outpacing the unemployment of the general population.^{1,5,19,33,34} The objective conditions of their physical condition rather than the perception of health would influence the lack of work.

Patients with RTCD onset at pediatric age lived with their parents (61%). This contrasts with those who had RTCD in adulthood and the general population. Patients with disease onset at pediatric age do not separate from their families.^{5,9} This is interpreted as a lack of independence and maturity in which the patient and his family participate bidirectionally. Chronic diseases from childhood increase dependence on parents and decrease patient autonomy.35 The inverse relationship between transplant time (dialysisfree period) and living with parents indicates that this period allowed patients to mature and have greater autonomy 11.6% of patients with pediatric-onset RTCD were living in a couple with children vs. those who started RRT at age adult and the general population. The burden of illness was reflected in the lack of maturity to share life with another person.

Patients with RTCD before age 12 have more complications and sequelae even after a successful kidney transplant. When dividing the adult patients with the RTCD group before and after age 12, we found no differences in any of the variables studied.

This study has limitations. We have not found KDQOL-36 publications that study adults with the onset of RTCD at pediatric age to compare with our results; it should involve a more significant number of patients, a wider age range, and different socioeconomic classes.

However, KDQOL-36 was able to discriminate information about HRQL in adult hemodialysis patients who started RTCD as children/ adolescents or adults. The internal consistency analysis of KDQOL-36 was performed using the Cronbach alpha coefficient as an indicator of instrument reliability, and it showed acceptable values in all domains.

CONCLUSIONS

Adult patients with RTCD who started their disease at a pediatric age have a good perception of HRQL despite the long period of RRT. They have a good level of education, but the lack of work, independent living, and life in a couple and few children is related to a long and complex history of the burden of kidney disease.

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