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Efficacy of the ALL YOU NEED IS LOVE healthcare transition syllabus among pre- and posttransplant adolescents in Cali, Colombia

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Abstract

Background To achieve optimal outcomes, adolescents with chronic or end-stage kidney disease must undergo healthcare transition (HCT) preparation from a pediatric- to an adult-focused setting. The pediatric nephrology group at the Fundación Valle del Lili in Cali, Colombia, collaborated with the University of North Carolina Chapel Hill STAR_x Program and Hospital Infantil de México Federico Gómez to start an HCT preparation program using their tools. The objective of this study was to evaluate the efficacy of the “ALL YOU NEED IS LOVE” syllabus (Spanish version) and its effects on HCT readiness in young patients with kidney failure, including renal transplants.

Methods We conducted a pre-test/post-test quasi-experimental study without control group in 11- to 21-year-old consecutive patients with kidney failure followed at the Fundación Valle de Lili. Using the TRxANSITION Index, we measured HCT readiness skills before and after implementing the “ALL YOU NEED IS LOVE” syllabus, an educational curriculum delivered in three monthly 2-hour sessions. Analysis was performed using linear mixed models in R Studio software to evaluate intervention effects while accounting for participant characteristics.

Results We enrolled 35 patients (57% female, median age 15.4 years [IQR: 12.6–17.1]). Most patients (77%) had received dialysis pre-transplant and 68% had congenital anomalies of the kidneys and urinary tract. Mothers were primary caregivers for 85% of patients. Linear mixed models showed that post-intervention scores increased significantly across all measures ($\beta = 3.28$, 95% CI 2.64–3.92, $p < 0.001$ for transition scores; $\beta = 1.93$, 95% CI 1.48–2.38, $p < 0.001$ for parent scores; $\beta = 9.31$, 95% CI 7.66–10.96, $p < 0.001$ for total scores). College education was associated with higher baseline scores ($\beta = 2.38$, 95% CI 0.42–4.35, $p = 0.019$ for transition scores; $\beta = 7.58$, 95% CI 1.23–13.93, $p = 0.021$ for total scores). Male participants showed slightly lower initial scores ($\beta = -0.88$, 95% CI -1.76 to 0.00 , $p = 0.051$).

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Conclusion In this cohort of youth with kidney failure from Cali, Colombia, implementation of the Spanish version of the “ALL YOU NEED IS LOVE” syllabus was associated with significant improvements in HCT readiness. Linear mixed models demonstrated robust intervention effects across all domains, with educational level emerging as a significant moderator of intervention effectiveness. Further longitudinal studies are needed to evaluate the long-term impact and sustainability of these improvements in transition readiness scores.

Trial Registration This study was retrospectively registered at ClinicalTrials.gov (NCT06836544, <https://clinicaltrials.gov/ct2/show/NCT06836544>) on February 10, 2025.

Keywords Youth, Adolescents, Young adult, Chronic kidney disease, Kidney transplant, Healthcare transition and patient education

Background

The survival of youth with kidney failure has improved over the last few decades due to improved treatment, surgical techniques and closer interdisciplinary follow-up. Kidney transplantation remains the renal replacement therapy of choice in pediatric patients with kidney failure given its greater benefit over dialysis in terms of survival, quality of life, and cost-effectiveness. According to the RELATREP (Latin American Registry of Pediatric Kidney Transplantation), between 2004 and 2017, Colombia reported 244 kidney transplants in children between 5 and 17 years of age [1–5]. Prestidge et al. reported an increase in renal graft loss in patients without healthcare transition (HCT) preparation from pediatric- to adult-focused settings [6]. In adolescents, lower graft survival and a higher incidence of acute rejection have been associated with poor adherence to treatment [7, 8]. Programs and interventions for HCT preparation are necessary to improve outcomes [3, 8–17].

The University of North Carolina (UNC) STAR_x (Self-management and Transition to Adulthood with R_x = Treatment) Program created the “ALL YOU NEED IS LOVE” (*Adherence and Longitudinal Life skills for Youth, Nurturing Educational Environment on Disease Intelligent Self-management: Lasting Outcomes, Visionary Empowerment*) Syllabus, a low-literacy patient education intervention that follows the UNC TR_xANSITION Index. This index was translated to Spanish in collaboration with the renal divisions of Hospital Infantil de México Federico Gómez in México City, Universidad de Puerto Rico and our team in Cali, Colombia, to assess youth’s knowledge about their illness and treatment and skills related to health self-management [18–21]. The Spanish version of the “ALL YOU NEED IS LOVE” syllabus has been tested among youth and young adults with kidney failure in the USA and México, revealing a significant improvement in HCT preparation [21, 22].

Our objective was to evaluate the efficacy of the Spanish version of the “ALL YOU NEED IS LOVE” syllabus based on changes in the TR_xANSITION Index in a group of pre- or post-transplant youth treated at Fundación

Valle del Lili (FVL) and their primary caregiver in Cali, Colombia.

Methods

Study Design

This study employed a pre-test/post-test quasi-experimental without control group design to evaluate the effectiveness of the “ALL YOU NEED IS LOVE” syllabus on HCT readiness using the TR_xANSITION Index. Quasi-experimental research designs evaluate interventions without using randomization and are particularly valuable when randomized controlled trials are impractical, unethical, or impossible to implement in real-world settings [23].

This approach was selected because:

- It allows for evaluation in natural educational settings
- It enables measurement of change over time
- It provides a practical approach when randomization is not possible

Study location and population

The study was performed at the pediatric nephrology service located in the FVL in Cali, Colombia. At our institution, kidney failure patients are cared for by a multidisciplinary team that includes the specialties of pediatric nephrology, pediatric endocrinology, abdominal organ transplant surgery, nursing, nutrition, social work and psychology.

Consecutive pre- and posttransplant youth aged 11–21 years along with their primary caregivers were enrolled from April 2016 to May 2017 after providing informed consent and/or assent. For minors, their primary caregivers’ consent was obtained. Participants were recruited based on their ability to participate in three consecutive sessions scheduled on the same day as their clinic visits. The socioeconomic stratum was defined based on the stratification of the public services provided by the housing. This classification has a range between 1 and 6, where 6 represents the highest socioeconomic conditions and 1 represents the lowest.

Inclusion and exclusion criteria

The study included patients aged 11–21 years along with their primary caregivers, who were either renal transplant recipients or in a renal transplant protocol, provided they were under follow-up by the Nephrology Service at Fundación Valle del Lili. Patients were excluded if they did not sign the informed consent and/or assent to participate in the study. Additionally, patients were excluded if they lost their care agreement with Fundación Valle del Lili due to administrative reasons related to their health insurance provider.

Data collection

A sociodemographic survey was administered. Clinical variables were collected from the participants' electronic health records in the SAP (Systems, Applications, Products in Data Processing) Software and from the "Trial" database with ID "10" in BDClinic (Clinical Database Management System). Acute rejection events were defined as those with histopathological evidence from renal graft biopsy or a clinical diagnosis.

Intervention

The "*ALL YOU NEED IS LOVE*" syllabus consists of interactive class sessions with groups of 15–20 patients and their primary caregivers using the "Self-Management Booklet" (AYNIL manual) educational tool created by the UNC group, led by Dr. Maria Ferris, translated at the Federico Gomez Hospital (Dr. Mara Medeiros) and adapted at our institution. (See Appendix 1). This syllabus covers the basic concepts of kidney failure, kidney transplantation, healthcare transition and self-care. A total of three sessions were held (one each month). In each of the sessions, two of the six educational chapters were covered until they were completed. The duration of the program was three months. The six sections are as follows [18, 19, 21, 22, 24, 25]:

Week 1: Introduction to the Kidneys

Week 2: Chronic Kidney Disease, Medication Management

Week 3: Making Healthy Choices

Week 4: Learning about Self-Care

Week 5: Becoming Independent

Week 6: Review and Self-assessment

A pilot test was performed in twenty adolescents with kidney failure or who underwent solid-organ transplantation (for reasons other than the kidney). Once the intervention underwent minor adjustments (a few terms were adapted to our culture), it was then applied to patients in the pediatric kidney transplant program.

Measuring instrument/outcome

To evaluate the efficacy of the "*ALL YOU NEED IS LOVE*" syllabus, the change in the UNC TRxANSITION

Index score was used as an outcome. This index was previously validated in Mexico from the original instrument (the UNC TRxANSITION Index™ version 3) [18, 19]. The acronym TRxANSITION in the survey corresponds to the ten sections evaluated, which were as follows:

T	Type of chronic disease
R _x	Prescriptions
A	Adherence to medical treatment
N	Nutrition/Special Diet
S	He knows how to organize his own life
I	Reproduction Information
T	School/Work
I	Health Insurance Information
O	Organize your support resources
N	New health providers

The UNC TRxANSITION Scale™ incorporates caregiver-specific questions to assess their knowledge and involvement in the patient's care. Each patient was accompanied by one primary caregiver, who was assessed alongside the patient. This dual evaluation reflects the interconnected roles of patients and caregivers in the healthcare transition process, ensuring comprehensive support for adolescents managing chronic kidney disease.

The TRxANSITION Index was quantified as two scores, the total raw score (number of questions), with a maximum of 32 points, and the abbreviated score (sum of all 10 subdomains), with a maximum of 10 points. This intervention involved both the primary caregivers and the patients, along with their corresponding scores.

Maturity was assessed by the psychology team through standardized evaluations that considered cognitive, emotional, and social development factors. These assessments ensured that participants demonstrated sufficient developmental maturity to engage meaningfully in the research. This approach aligns with best practices for evaluating children's capacities, as described by Henderson-Dekort et al. [26], who emphasize the use of age-appropriate methods to capture children's perspectives and insights effectively [26].

Statistical analysis

Descriptive statistics were used to summarize the sample characteristics. For continuous variables, medians and interquartile ranges (IQRs) were reported due to nonnormal distributions. Categorical variables are summarized using frequencies and percentages. Cross-tabulation was performed to explore sample characteristics. Fisher's exact test was used to determine associations between categorical variables.

To evaluate the effectiveness of the STARx transition program in preparing patients and primary caregivers, linear mixed models were used to analyze the longitudinal data, accounting for repeated measurements and individual variation. Three separate models were fitted

for different outcome measures: Transition Score, Parents Score, and Total Score. Fixed effects included gender, age group (13–16, 17–21), caregiver type (mother, father, both), education level (elementary, high school, college), and intervention status (pre/post). Given sample size limitations, we used educational level as a proxy for socioeconomic status while acknowledging its limitations. Random effects were included at the participant level to account for individual variations. The models' goodness of fit was assessed using marginal and conditional R^2 values, and the intraclass correlation coefficient (ICC) was calculated to evaluate the proportion of variance explained by individual-level clustering.

Scores changes (total, transition, and parent) were dichotomized at the 50th percentile to classify into “High Change” and “Low Change” groups. Graft survival was analyzed using Kaplan-Meier curves stratified by these dichotomized score changes, with log-rank tests for group comparisons. Graft loss was defined as return to

dialysis or retransplantation. Survival analysis was conducted using R software version 4.4.2 (Fig. 1).

Sample size

We used convenience sampling for this study, enrolling consecutive eligible patients who attended the pediatric nephrology service at FVL during the study period. While no formal a priori sample size calculation was performed, post-hoc power analyses demonstrated adequate statistical power. With our final sample size ($n = 69$ observations; 34 pre tests and 35 post test results), the study achieved > 99% power to detect the observed effects in all three models (Transition, Parents, and Total scores), with large effect sizes (f^2 ranging from 1.304 to 1.469) and R^2 values between 0.566 and 0.595. (Supplementary Material 1).

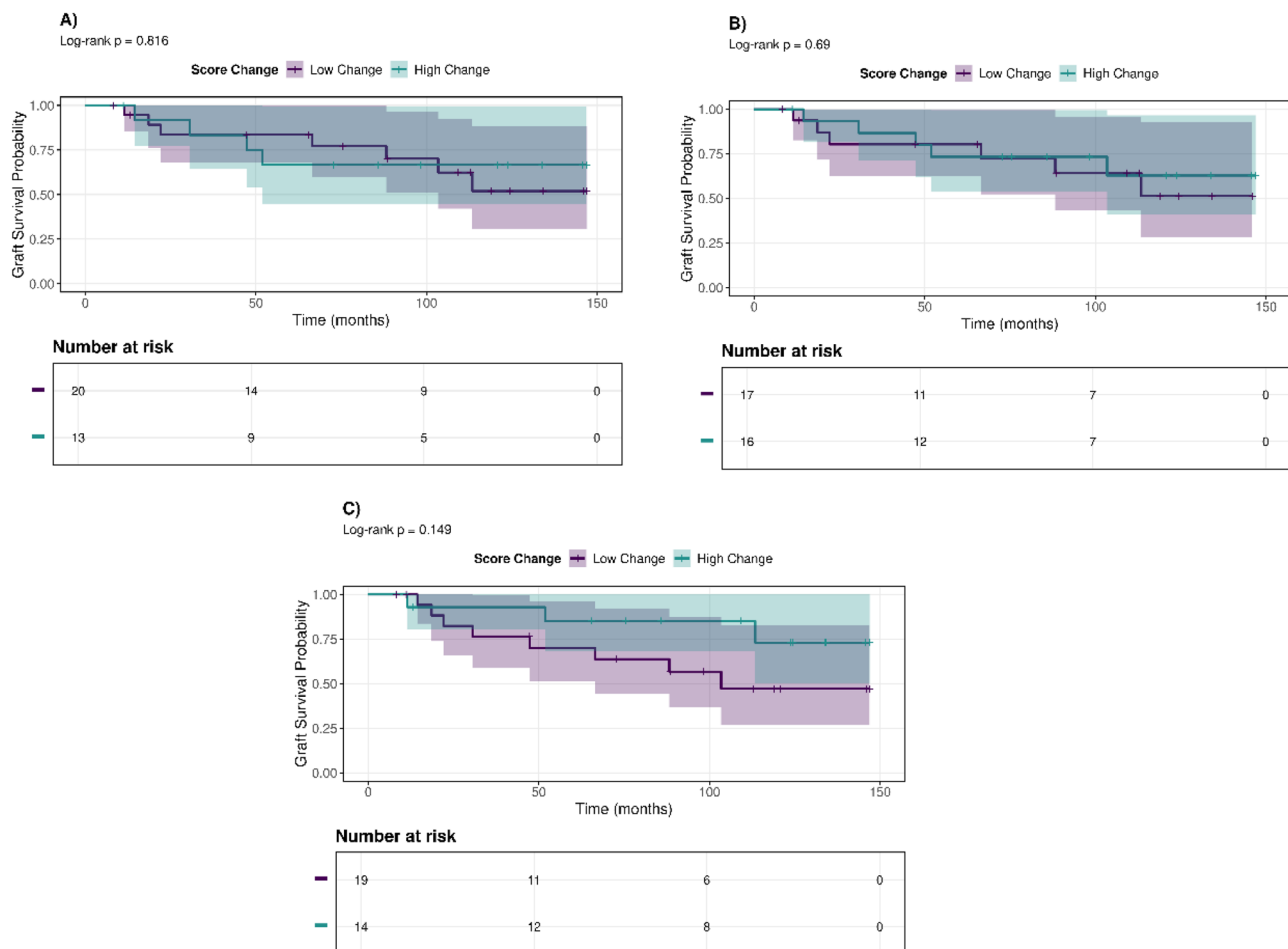


Fig. 1 Kaplan–Meier curves for graft survival stratified by score changes. **A** Total score change (dichotomized at median of 9.0 points); **B** transition score change (dichotomized at median of 3.1 points); **C** parent score change (dichotomized at median of 5.5 points). Log-rank test p -values shown for each comparison. Numbers at risk displayed at the bottom of each panel

Results

A final sample of 35 patients alongside with their primary caregivers was enrolled (29 had a functional graft, and 6 were in the pretransplant stage) with the following characteristics: 57% female. 63% came from the Department of Valle del Cauca, more than half belonged to the very low (37%) or low (31%) socioeconomic strata, and 11.4% came from rural areas. 46% had completed secondary education, and 9% had attained higher education. In terms of occupation, 80% were students.

The majority (77%) were on dialysis prior to kidney transplantation (89%, $n = 24$; $n = 3$, 11%; on hemodialysis), and 23% were preemptive transplants. At baseline, 29 patients had a functional graft, with a median creatinine level of 1.1 mg/dL (IQR 0.9–1.3) and a median estimated glomerular filtration rate (eGFR) according to Schwartz's 2009 revised formula of 58 mL/min/1.73 m² (IQR 51–66) [27, 28].

The median pre-transplant height z-score was -2.7 (IQR: -3.5 to -1.6), compared to the post-transplant height z-score of -1.95 (IQR: -2.3 to -1.2), indicating an improvement in z-scores. The immunosuppressive regimen consisted of tacrolimus, mycophenolate mofetil and steroids in 88% of patients, followed by cyclosporine, mycophenolate mofetil and steroids in 8.6%. Among transplant recipients, 24% had at least one episode of

acute rejection confirmed by kidney biopsy in the first year posttransplantation (Table 1). The primary caregivers in most cases were mothers (86%), 27% were older than 50 years of age, 68% had a low or very low socioeconomic status, 63% had a secondary education, and 17% had a higher education (see Table 2), similar to the findings of a previous publication from our group [14].

The linear mixed models analysis revealed significant findings across multiple dimensions. For the Transition Score evaluated in patients, being male was associated with a slightly lower score (-0.88 , 95% CI -1.76 to 0.00 , $p = 0.051$). Higher education levels showed positive associations, with college education demonstrating a significant increase (2.38 , 95% CI 0.42 – 4.35 , $p = 0.019$) compared to primary education. The post-intervention effect showed a substantial improvement in scores (3.28 , 95% CI 2.64 – 3.92 , $p < 0.001$).

For the Parents Score, the post-intervention effect was also significant (1.93 , 95% CI 1.48 – 2.38 , $p < 0.001$). While gender and education level showed some variations, these were not statistically significant. The model showed good fit with a marginal R^2 of 0.566.

The Total Score analysis demonstrated several key findings. Male participants showed significantly lower scores (-3.38 , 95% CI -6.28 to -0.49 , $p = 0.024$). College education was associated with significantly higher scores

Table 1 Patient clinical and anthropometric variables

Variables	n (%)	Median (IQR)
Age at the time of transplant (years), $n = 34^*$		12.1 (9.1–14.4)
Height pretransplant (cm)	–	128 (114–142)
Z score, $n = 34$		-2.7 (-3.5 to -1.6)
Dialysis pretransplant $n = 35$	27 (77.1)	–
Preemptive transplant	8 (22.9)	
Disease at baseline, $n = 35$		
Congenital malformation of the kidney and genitourinary	24 (68.6)	–
Glomerulopathies	9 (25.7)	
Other causes	2 (5.7)	
Sensory disability conditions	2 (2.9)	–
Initial immunosuppression scheme		
Cyclosporine + Mycophenolate + Steroids	3 (8.6)	
Tacrolimus + Mycophenolate + Steroids	31 (88.6)	–
Without data*	1 (2.8)	
Rejection episodes, $n = 29$		
None	22 (75.9)	
One	7 (24.1)	–
Creatinine posttransplant, $n = 29$ (mg/dL)	–	1.1 (0.9–1.3)
Height posttransplant (cm), $n = 29$		149 (139–157)
Z score, $n = 24^{**}$	–	-1.95 (-2.3 to -1.2)
eGFR posttransplant, $n = 29$ (mL/min/1.73 m ²)	–	58 (51–66)

eGFR estimated glomerular filtration rate; CMP cyclosporine-mycophenolate-steroid; MST tacrolimus-mycophenolate-steroid

*The pretransplant data of one of the patients (date of transplant, pretransplant weight, pretransplant height and initial immunosuppressive scheme) are not available since the study was performed extrahospitally

Five of the kidney transplant recipients with functional grafts were of legal age at the time of inclusion in the study, which did not allow calculation of the Z score in these patients. *

Table 2 Sociodemographic variables (n = 35)

Variables	Value
Age at the time of inclusion in the study in years (n = 35)	15.4 (12.6–17.1)
Median (IQR) Min–Max	11–19
Age 11–14 years	14 (40.0%)
Age 15–21 years	21 (60.0%)
Time since renal transplant at study time (months), n = 29	
Median (RIC)	37.8 (13.7–67.2)
Min–Max	0.7–194.3
Sex	
Male	15 (42.9)
Female	20 (57.1)
Place of residence, n (%)	
Valle del Cauca	22 (62.9)
Nariño	5 (14.3)
Región cafetera	4 (11.4)
Cauca	3 (8.6)
Norte Santander	1 (2.9)
Educational attainment of adolescent n (%)	
Primary school	16 (45.7)
Middle school	16 (45.7)
Superior	3 (8.6)
Primary caregiver n (%)	
Mother	30 (85.7)
Father	2 (5.7)
Mother and father	1 (2.9)
Grandfather	2 (5.7)
Socioeconomic stratum, n (%)	
1	13 (37.1)
2	11 (31.4)
3	11 (31.4)
Occupation, n (%)	
Student	28 (80)
Employed	2 (5.7)
Unemployed	5 (14.3)

(7.58, 95% CI 1.23–13.93, $p=0.021$). The post-intervention effect was substantial (9.31, 95% CI 7.66–10.96, $p<0.001$). The model demonstrated good explanatory power with a marginal R^2 of 0.580 and a conditional R^2 of 0.747. (Table 3).

The most notable improvements of the TRxANSITION Index domains were observed in disease knowledge, school/work management, and knowledge about new healthcare providers, all reaching maximum or near-maximum scores post-intervention. Initially low self-care skills showed modest but significant improvement, while domains such as medication management, adherence, and nutrition demonstrated substantial optimization. All

improvements were statistically significant ($p<0.001$), except for support groups ($p=0.0032$).

The random effects structure showed varying levels of individual-level variance (τ_{00}) across the models, with the Total Score model showing the highest individual-level variance (7.44). The Intraclass Correlation Coefficient (ICC) ranged from 0.18 to 0.40, indicating moderate within-subject correlation. (Table 4).

During the follow-up period (median 37.8 months, IQR: 13.7–67.2), no deaths were recorded. Seven patients (20%) experienced graft loss, all occurring beyond the year post-transplant. The median values used for score change dichotomization were 9.0 points for total score, 3.1 points for transition score, and 5.5 points for parent score.

Kaplan–Meier analysis showed no significant differences in graft survival between high and low score change groups (total score: log-rank $p=0.816$; transition score: $p=0.690$; parent score: $p=0.149$). (Fig. 1)

Discussion

The present quasiexperimental study evaluated the effectiveness of the “ALL YOU NEED IS LOVE”, a low-literacy HCT preparation syllabus, among pediatric pre- and post-HSCT youth in Cali, Colombia. We found significant increases in the total (raw and abbreviated) TRxANSITION Index scores from youth and primary caregivers in all subdomains. The analysis of the TRxANSITION Index domains revealed significant improvements across all areas evaluated after the intervention (Table 4).

Furthermore, the linear mixed model analysis highlights the robustness of these improvements, with post-intervention scores consistently emerging as strong predictors of better performance across all subdomains. Notably, higher educational attainment, particularly at the college level, was linked to significant gains in transition readiness. These findings emphasize the dual role of targeted interventions and educational support in facilitating successful health transitions, providing evidence of broader applicability across diverse populations.

These results indicate the effectiveness of this intervention, similar to the findings of cohorts in Mexico and the USA (20 and 21). In the characterization study of our patients, the exploration of the relationship between age and educational attainment revealed that, despite living with a chronic illness, most adolescents maintained an educational level appropriate for their age. This finding facilitated the implementation of the second phase of the transition program—STARx [29]. In Latin America, HCT programmes for pediatric patients with kidney disease are scarce, and the educational syllabus ALL YOU NEED IS LOVE represents a step toward affecting this change, as has been shown in Mexico [14]. At Garrahan Hospital in Argentina, Dr. Adragna et al. applied an HCT program

Table 3 Linear mixed models for scores pre- and postintervention. The intercept indicates the expected baseline value of each score when all predictors in the model are zero, serving as the reference point from which other effects are measured

Predictors	Transition score			Parents score			Total score		
	Estimates	IC (95%)	p	Estimates	IC (95%)	p	Estimates	IC (95%)	p
(Intercept)	6.70	4.84–8.56	<0.001	7.73	6.63–8.83	<0.001	19.36	13.26–25.46	<0.001
Male	−0.88	−1.76 to 0.00	0.051	−0.52	−1.04 to 0.00	0.051	−3.38	−6.28 to 0.49	0.024
Age 11–14	0.04	−1.23 to 1.32	0.948	0.41	−0.35 to 1.17	0.275	0.30	−3.89 to 4.49	0.883
Age 15–21	−0.61	−2.05 to 0.82	0.387	0.43	−0.42 to 1.28	0.312	−2.28	−7.00 to 2.44	0.330
Primary caregiver [mother]	−0.65	−2.37 to 1.08	0.448	−0.14	−1.15 to 0.87	0.778	−1.85	−7.52 to 3.82	0.507
Primary caregiver [father]	−1.71	−4.26 to 0.84	0.181	0.62	−0.88 to 2.12	0.404	−3.92	−12.27 to 4.44	0.344
Primary caregiver [father and mother]	−1.09	−4.01 to 1.83	0.448	−0.40	−2.11 to 1.32	0.638	−1.52	−11.11 to 8.08	0.747
Education [high school]	0.57	−0.54 to 1.68	0.303	−0.40	−1.04 to 0.25	0.222	1.43	−2.22 to 5.07	0.429
Education [college]	2.38	0.42 to 4.35	0.019	−0.60	−1.77 to 0.57	0.300	7.58	1.23 to 13.93	0.021
Post intervention score	3.28	2.64 to 3.92	<0.001	1.93	1.48 to 2.38	<0.001	9.31	7.66 to 10.96	<0.001
Random effects									
σ^2	1.69			0.83			11.29		
τ_{00}	0.37 _{id}			0.00 _{id}			7.44 _{id}		
ICC	0.18						0.40		
N	35 _{id}			35 _{id}			35 _{id}		
Observations	69			68			69		
Marginal R ² /Conditional R ²	0.595/0.667			0.566/NA			0.580/0.747		

Table 4 Score improvement by domains

Characteristics*	Pre-intervention	Post-intervention	p-value
Disease	0.66 (0.33–1)	1.0 (1.0–1.0)	<0.001
Medications	0.75 (0.50–0.88)	1.0 (0.88–1.0)	<0.001
Adherence	1 (0.67–1.0)	1.0 (1.0–1.0)	0.001
Nutrition	0.66 (0.55–0.83)	1.0 (0.83–1.0)	<0.001
Self-care	0.33 (0.16–0.5)	0.5 (0.42–0.71)	<0.001
School/Work	0.50 (0.0–0.75)	1.0 (1.0–1.0)	<0.001
Insurance providers	0.50 (0.38–0.63)	0.88 (0.75–1.0)	<0.001
Support groups	1 (0.5–1.0)	1.0 (1.0–1.0)	0.0032
New doctors	0.25 (0.0–0.5)	1.0 (0.75–1.0)	<0.001

*Median [interquartile range]

to 100 patients aged 16–19 years and reported that these patients had difficulties managing their own lives when they were being transferred to adult centers, especially in relation to autonomy and ability to function in the health system [14].

HCT preparation for adolescents and young adults with chronic conditions is highly important for preventing worsening of underlying disease or graft/patient survival. Adolescence is a period of self-understanding and introspection when youths learn responsibility and self-care and their primary caregivers begin to delegate responsibility to their children. Therefore, it is essential to initiate HCT preparation, scheduled transfer and a follow-up period. The American Academy of Pediatrics and the American Society of Transplantation recognize the importance of proper transition of health care from child-oriented to adult-oriented by supporting the creation of transition programs [6, 30–33]. The 2011 consensus of the International Society of Nephrology and the International Pediatric Nephrology Association provided

standards for HCT [28], such as the need for individualized HCT plans and dedicated transition leaders and collaboration between pediatric and adult care services. In general, the proposed components are the following: transition proposal (evaluation and gradual preparation), transfer (individualized, agreed upon and at the right time) and evaluation of the transition process (education, multidisciplinary intervention and the formation of a group dedicated to optimizing this process).

Long-term outcomes of renal graft, as well as treatment adherence, were highlighted in a systematic review in which an additional HCT protocol [34, 35] RISE to Transition [Recognition, Insight, Self-Reliance and Establish] was proposed for 3 stages: pretransition stage (14–18 years), active transition stage (18–21 years) and posttransition stage (21–26 years). Evidence suggests that implementing a transition program improves long-term outcomes in this group of patients [36, 37]. It is important to highlight that, “the other cause” of ESKD in our group was 5.5%, very low compared to patients from Cantú-Quintanilla validation, which was 46.6%. It means, earlier diagnosis implies better education for the patients and their families.

Different to RISE protocol, similar to Cantú- Quintanilla et al. [20] and despite, the ideal age to start a transition program is at 14 years old, some children who have been receiving renal replacement therapy since the age of 7–8, may be capable of taking responsibility for their treatment obligations before reaching 14. In our case, children who participated between the ages of 11 and 14 (40%) Table 2, had sufficient developmental maturity to engage in the research work alongside their families. The

Transition scores were not significantly different between 11 and 14 years (0.04, CI -1.23 to 1.32, $P=0.098$) and 15–21 years (-0.65, CI -2.05–0.82, $P=0.387$) Table 4.

In a study conducted at Massachusetts General Hospital in Boston, a group of surgeons evaluated the impact of the subspecialty care model (7.7%) vs. the integrated posttransplant care model (92.3%, affiliated pediatric centers integrated with an adult center) on 6762 kidney transplant recipients during the HCT age of 13–21 years; a high percentage of patients lost during follow-up in the specialized model (38.3%) was found, but a lower risk was found in the integrated model group (33%) (OR 0.67 CI 0.54–0.82, $P<0.01$), which indicates improved outcomes. In addition, greater loss to follow-up was also found for men (OR 1.28, CI 1.12–1.47, $P<0.001$) and for those without private insurance (OR 1.47, CI 1.23–1.75, $P<0.001$), while the loss to follow-up was lower for those of African race (OR 0.76, CI 0.63–0.91, $P<0.001$). The long-term achievements of integrated services (children-adults) allow for better adherence to the program during the transition period [38].

Among low-middle income countries, a South African program reported their 20-year program at the Red Cross War Memorial Children's Hospital and the adult-focused program at Groote Schuur Hospital. Their model introduced a 1-h session where each pediatric patient had a peer-mentor chosen from within the group of patients with kidney failure, focusing on age-friendly activities and with the goal of stimulating the adolescents' connections. As a special recommendation, they propose collaborative multidisciplinary teams for adolescents [36]. Another publication suggested that motivational interviewing could be an effective tool for empowering patients and primary caregivers to assume responsibility and maintain recovery [36].

It is essential to highlight the role played by an HCT programme established in hospitals that share the care of children and adults. This integrated system has the advantage of allowing greater interaction and follow-up during adolescence and young adulthood. Our work was carried out in a hospital with these characteristics, where clinical experiences in HCT preparation were shared with adult and transplant nephrologists through interdisciplinary collaboration among nurses, social workers, psychologists and nutrition teams at weekly meetings. This HCT preparation is maintained during the pre- and postkidney transplant periods.

We previously characterized the study population before the implementation of the present study protocol, noting that the UNC TRxANSITION Index was greater in older patients and in those who underwent kidney transplantation [38]. A strength of our study is the use of an integrated hospital model for pediatric and adult nephrology services, which could promote a greater

sense of security in patients and their families, as they perceive better care-related follow-up by both pediatric- and adult-focused providers [18, 19].

In our study, we considered that the adequate level of education achieved by the patients, as well as the role of the primary caregivers, could contribute to the improvement in the scores obtained in the UNC TRxANSITION Index after going through the STARx program. This approach allowed for better adherence to treatment and posttransplant follow-up. The empowerment of patients and families to achieve adequate management and control of medications, as well as all psychological support in the adolescent period, are part of a programme focused on the adherence and well-being of transplant patients [39, 40]. A limitation of our study is the sample size, which prevents generalization of the findings.

Conclusions

The early efficacy of the “ALL YOU NEED IS LOVE” Syllabus for HCT preparation among adolescent kidney transplant patients or in the pretransplant stages was demonstrated by significant improvements in the TRxANSITION Index among pre- and post kidney transplant youth and caregiver scores. However, additional studies with prospective follow-up data in this group of patients in Latin America are needed to analyze and evaluate the effectiveness of an HCT program for outcomes such as allograft survival, patient survival, and rejection episodes. Using validated tools for evaluating interventions will improve HCT preparation before, during, and after the transfer of care.

Abbreviations

FVL	Fundación Valle del Lili
HCT	Healthcare transition
RELATREP	Latin American Registry of Pediatric Kidney Transplantation
STARx	Self-management and Transition to Adulthood with Rx=Treatment
SAP	Systems, Applications, Products in Data Processing
UNC	University of North Carolina

Supplementary information

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Supplementary Material 1

Supplementary Material 2

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Author contributions

MR conceived the original study idea and provided intellectual insight. JMR, VAO and JMF wrote the manuscript and obtained and reviewed all necessary references. AMP and AP were responsible for all editing and receiving approval from all authors. MMB performed the statistical analysis and developed tables. All authors collected the data and provided significant intellectual insight into

the study and the manuscript editing of each version. MF revised multiple versions of the manuscript, offered major intellectual insight into the research. All authors contributed to and approved the final manuscript.

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Data availability

The datasets generated and analyzed during the current study are not publicly available due to data privacy limitations but are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

This study was conducted in accordance with the relevant ethical guidelines and regulations, including the Declaration of Helsinki. Ethical approval was obtained from Biomedical Research Ethics Committee (CEIB) of the Fundación Valle del Lili (FVL), under approval number 118–2016 dated March 28, 2016. Written informed consent was obtained from all participants or their legal guardians, as applicable. Additionally, assent was obtained from all children old enough to provide it, in accordance with ethical guidelines. To protect the anonymity and confidentiality of the participants, their data were anonymized. The surveys and interventions were administered to youth and primary caregivers in a suitable place and environment to maintain privacy and fidelity by two trained nursing students and a physician.

Consent for publication

Not Applicable.

Competing interests

The authors declare that they have no conflict of interest in relation to this research and its publication.

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