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Validation of the UNC TR$_x$ANSITION Scale™ Version 3 Among Mexican Adolescents With Chronic Kidney Disease

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Background There is a lack of valid health care transition readiness (HCT) scales in Spanish.
Objective: To provide initial validation of the UNC TR$_x$ANSITION Scale™ among Mexican adolescents and young adults (youth) with chronic kidney disease (CKD).
Methods: We used the professionally translated/back translated, provider-administered UNC TR$_x$ANSITION Scale™ (Ferris et al., 2012). This 33-question scale measures HCT in ten sub-scales including knowledge about diagnosis or treatment, diet, reproductive health, school/work, insurance, ability to self-manage and looking for new health providers. Its maximum score is 10.

We enrolled 163 Mexican adolescents (48.5% females) with CKD stage ≥ 3, mean age of 15.1 years (±2.1) and whose primary language is Spanish. There were 15 patients on hemodialysis (9.2%) and 30 transplant recipients (18.4%). Results were compared to those reported in adolescents with chronic conditions from the USA.
Results: Our cohort's overall median total score was 5.9. Patients ≥ 16 years old had a median total score of 6.4, whereas younger patients had median score of 5.6 ($p < 0.05$). Transplant patients had greater scores in the total and the sub-scales of medication knowledge, issues of reproduction, insurance, trade/work and adherence ($p < 0.05$). When comparing the total score (by age), results from our Mexican youth were similar to those reported in youth from the USA.
Conclusions: In our Mexican cohort of youth with CKD, health care transition readiness is greater in older patients and in transplant recipients. Our cohort's overall score is low, indicating the need for a health care transition preparation program. The UNC TR$_x$ANSITION Scale™ results in Mexican youth with CKD are comparable to findings in youth from the USA.

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PATIENTS WITH CHRONIC kidney disease (CKD) are increasing in numbers worldwide in all age groups (Warady & Chadha, 2007), and the burden is higher in disadvantaged

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populations (Garcia-Garcia, Jha, & World Kidney Day Steering, C, 2015). The median incidence of renal replacement therapy in children aged 0–19 across the world in 2008 was 9 per million of the age-related population (range 4 to 18), unfortunately there is no precise information about the incidence of early stages of CKD in children (Harambat, van Stralen, Kim, & Tizard, 2012). The management of CKD in the past decades has seen great progress; reflected in increasing survival rates (Ferris, Gipson, Kimmel, & Eggers, 2006) and improved dialysis- and transplantation-related procedures. Nevertheless, it has been reported that the 10-year graft survival is highest among recipients younger than 5 years and lowest among adolescents (Dharnidharka, Fiorina, & Harmon, 2014). In adolescents, the most common causes of graft loss are acute and chronic rejection episodes and immunosuppression non-adherence (Bobanga et al., 2015). In a USA national registry, 14–15 year old patients with public insurance are at the greatest risk of kidney transplant loss (Andreoni et al., 2013). Efforts to address this patient-safety issue need to be implemented to improve graft and patient survival.

Pediatric patients with CKD or ESKD require follow-up by a multidisciplinary team that includes nephrologists, psychologists, social workers, and nutritionists among others. It is recommended that transfer from pediatric- to adult-focused nephrology services should occur after efforts have been made to prepare the youth and the necessary patient care information has been delivered to the receiving adult-focused providers (Bell, 2007; Watson et al., 2011) to avoid poor patient outcomes (Watson, 2000). Health care transition (HCT) is an active process that attends to medical, psychosocial and educational or vocational needs, whereas transfer refers only to the change from one health care professional to another (Bell, 2007). Learning CKD or ESKD self-management skills involves a number of complex medical concepts (e.g., dietary restrictions, medication administration and for some, self-catheterizations or home dialysis). HCT also includes healthcare decision-making, self-advocacy eventual change from parent/guardian-directed care to self-management (Sawicki et al., 2011). In Mexico, youth are transferred to adult-focused care at 14–18 years of age, depending upon their health system. There are no institutional HCT programs in the country, and in general, patients are sent to an adult-focused clinic with a health summary.

In recent years, there has been a growing interest in HCT preparation as poor outcomes have been described in an unplanned process (Watson, 2000). The assessment of the youth's HCT readiness is critical for planned interventions, before the transfer to adult-focused health care takes place (Fenton, Ferris, Ko, Javalkar, & Hooper, 2015).

The UNC TR_xANSITION Scale™ version 3 is a provider-administered, disease neutral questionnaire that measures and verifies (through the medical record), the HCT and self-management skills in youth with chronic conditions. It covers ten global areas (sub-scales): 1) type of chronic illness, 2)R_x = medications, 3) adherence, 4) nutrition, 5) self-management, 6) issues of reproduction, 7) trade/school, 8) insurance issues, 9) ongoing support, 10) new health care providers. Each sub-scale is given a score of 0, 0.5 or 1.0, with a maximum possible score of 10. It can be used as a diagnostic and evaluation tool for HCT readiness (Ferris et al., 2012). The English and professionally translated/back-translated Spanish versions are available at the following website: http://www.med.unc.edu/transition. The aim of our study was to provide further validation of this scale in a Spanish version among Mexican youth with CKD or ESKD.

Methods

The UNC TR_xANSITION Scale™ version 3 was translated to Spanish by a professional certified translator. A second certified translator not familiar with the original English version performed the back translation from Spanish to English. Later, a team composed by our co-investigators (GC, MF, MM and ML) compared the original and the back-translated versions and made the proper changes. All Spanish-speaking investigators approved the final document. From the original 33 items of the UNC TR_xANSITION Scale™ we kept 32 items, since the item "Trade/School" was related to insurance in full-time college students and was not applicable to the Mexican health system. While the health coverage is different in Mexico (patients with no private insurance still have access to health services, but they still have to pay for their medications), we still asked some of the insurance-related questions (see Appendix 1).

Spanish-speaking patients older than 10 years and treated at the "Hospital Infantil de Mexico Federico Gomez," were invited to participate. This national referral center is a public institution funded by the Mexican government and private donations. Patients eligible for services at this institution have no private insurance coverage. To qualify for the study, participants with the diagnoses of CKD stage $\geq$ 3 or ESKD had to speak Spanish as their primary language.

Data were collected during a 9-month period from September 2013 to May 2014. The UNC TR_xANSITION Scale™ was administered by a trained psychologist to deliver the questions and answer rating. The parents were allowed to be present during the interviews, but were asked to remain silent. The psychologist verified the patient skills based on clinical chart information. The study was approved by our institution's ethics committee. All participants and their parents gave written assent/consent before the interviews.

Statistical Analysis

Analyses were performed using GraphPad version 5.0 for Mac Os X software. The distribution of variables was analyzed by Kolmogorov–Smirnov test. Descriptive statistics are reported as percentages for categorical variables, mean ± standard deviation for normally-distributed