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ORIGINAL ARTICLE

Assessment of knowledge and autonomy for the transition from adolescent toward adult care

Evaluación de conocimientos y autonomía para la transición de adolescentes hacia la atención de adultos

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What do we know about the subject matter of this study?

The transition from pediatric to adult care for adolescents with chronic conditions requires a stepped process. We recommend having instruments that help evaluate the degree of preparation of these patients.

What does this study contribute to what is already known?

We provide a clinical instrument with expertly validated content to assess the degree of preparation of adolescents with chronic conditions for transition to adult care.

Abstract

In the last decades more and more children survive with complex health conditions, requiring a transition from pediatric to adult care. It is essential to have instruments that provide information on the level of preparation of patients for this process. **Objective:** To create and validate a questionnaire to measure the readiness status of adolescent patients with chronic diseases in the transition process. **Patients and Method**: Based on international questionnaires, a self-report instrument was designed which was subjected to content validity by experts, and then to comprehension and feasibility tests in a pilot group. Subsequently, construct and reliability validation were performed through a factorial analysis after applied it to adolescents living with a chronic illness. **Results**: After the analysis made by 11 experts and the pilot group with 8 patients, we obtained an instrument that was fully answered by 168 teenagers (Average age 14.4 years). After construct validation, a 24-items instrument of high clinical relevance was developed, with 9 items with acceptable psychometric properties, which were highlighted in the final questionnaire. **Conclusion**: a self-report instrument aimed to measure the readiness of adolescents during the transition process to adult care is presented. The reported psychometric properties of the instrument were insufficient to consider it validated since the construct validity and reliability were only checked for 9 of the 24 items.

Keywords:
Transition to Adult Care;
Surveys and Questionnaires;
Self-report;
Chronic Illness;
Adolescent

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Introduction

More and more children with complex illneses manage to survive into adolescence and adulthood, requiring the transition from pediatric to adult care[1]. This milestone generates concern for patients, family, and pediatricians[2,3], and has proven to have a negative impact on patients' health[4-7]. In addition, in Chile, this change occurs in the middle of adolescence, which is not recommended[8].

Scientific societies, including the Adolescent Branch of the Chilean Society of Pediatrics, have stated that the transfer to adult care should be done through transition services using a dynamic and permanent method, focused on meeting the individual needs of each patient in the transition from childhood to adult life, in order to maximize their potential and functioning throughout life. This process should be provided through high quality, developmentally appropriate, uninterrupted, patient-centered services[8-12].

Since the transition process is so complex, it requires the adolescents to acquire knowledge and skills that result in improved self-care of their condition, which should be encouraged and evaluated during health check-ups. Although individual clinical practice does not necessarily require the use of questionnaires, they can help in the asesment of processes or their follow-up, diminishing the evaluator's subjective factor. Therefore, in the transition process, one of the recommendations is to have tools that allow to know the degree of preparation of the patient for the transfer[10,12]. There are diverse instruments validated, focusing on generic or specific chronic conditions, with different numbers of questions, and different scales of response. Some are designed to be answered by patients, some by parents, and some to be answered by both[13]. Although it is possible to access these studies, there are no locally developed instruments. In Spanish, the only instrument that exists is a validation of the Argentinean translation of a North American instrument (TRAQ-5), which was published during the preparation of this study[14]. It is important to point out that the instruments reported in the literature have been created in developed countries, which implies a cultural context different from the local one.

The goal of this study is to create a questionnaire that measures important elements in the preparation of adolescent patients with chronic illnesses for the transition to adult care, that is consistent with our reality, can be readily applied to young people in a limited time, and, finally, can be psychometrically validated.

The aim is to obtain an instrument that allows to comply with the recommendations of the transition process[10]. And by applying it, could contribute to the clinical teams having general information about the state of their patients before their transfer to adult services, and thus be able to guide improvement strategies in clinical practice or establish transition programs that can be measured with a standardized instrument.

Patients and Method

This study was approved by the Pediatric Scientific Ethics Committee of the Eastern Metropolitan Health Service.

We searched PubMed for validated instruments created to assess patients in their transition process and we reviewed in detail the articles that were fully published in that database (Table 1). At the same time, a Google search was made on existing transition programs in hospitals and we selected those that had a clinical instrument for the same purpose (Table 2).

Table 1. Validated instruments to assess readiness in transition

Name of the instrument	Target Condition
TRAQ[15]	Chronic Illness
UNCTRxANSITION[16]	Chronic Illness
Self-management skills assessment guide[17]	Chronic Illness
TRANSITION-Q[18]	Chronic Illness
SCIS[19]	Cystic Fibrosis
RTQ[20]	Renal Transplant
TRS[21]	Liver Transplant

Table 2. Transition programs available online

Transition Program	Website
Got Transition	http://www.gottransition.org/
Jacksonville Health & Transition Services	http://www.hscj.ufl.edu.jaxhats/
The Royal Children's Hospital Melbourne	http://www.rch.org.au/transition/
Transition to adult care: Ready Steady Go	http://www.uhs.nhs.uk/Ourservices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx
Children's Hospital at Westmead Transitional Care Policy	https://www.schn.health.nsw.gov.au/hospitals/kids-and-teenagers/teenagers/adult-hospital
On TRAC	http://www.ontracbc.ca

After reading and discussing the different items, dimensions, and scales of the questionnaires found, we designed a new one. This was elaborated by creating new questions based on the different instruments, as well as selecting and adapting others that were considered more pertinent to the cultural context.

TRAQ-5[15] and the Self-Management Skills Checklist of the Children's Hospital at Westmead (Table 2) were the instruments from which the most data was collected, since the first one has strong validation tests and the second one had cultural concordance of several items. The authors were contacted via email to obtain their approval to use the material.

Content validity

Content validity was evaluated by item according to the methodology suggested by Grant and Davis, based on the work of Hambleton et al, and then expanded by Martuza and Waltz et al.[22] Via e-mail, 11 experts agreed to participate: 3 adult specialists (internists), 6 adolescent specialists (adolescent pediatricians), and 2 experts in children's medicine (pediatricians).

The experts independently reviewed each of the items, assessing their relevance to the transition process using a 4-point scale: 1 = Not relevant, 2 = Not very relevant, 3 = Fairly relevant, and 4 = Very relevant[22,23]. The responses per item were tabulated into two categories, 'Not Relevant-Little Relevant' and 'Fairly Relevant-Very Relevant'. This last category was divided by the total number of responses, obtaining the item content validity index (I-CVI). Each index was adjusted against the probability that the experts randomly coincide in their evaluation, generating a new "Modified Kappa"(k*) index for each item, which was categorized according to the criteria established by Polit, Beck, and Owen[23].

They were also asked to evaluate the instrument qualitatively, and therefore, to express their opinions on the different dimensions and items. In addition, we asked about the age and context of the application of the instrument and general comments.

Scale

This scale was based on the stages of the transtheoretical model of change, which focuses on changing health behaviors; and applies to the acquisition oof new skills in the care and management of chronic conditions[25]. This scale was used in the TRAQ-5 instrument and validated within its study[15], but some modifications were made in order to coincide grammatically with the new items, and an expert in this model was asked to guarantee that they kept reflecting those stages.

Patient Recruitment

Convenience sampling, without stratification. Adolescents who had attended a medical checkup at Luis Calvo Mackenna Hospital were invited to participate. They were asked for their informed assent and the informed consent of one of their parents. The inclusion criteria were: to be within 12 and 19 years of age and to have a chronic condition. The exclusion criteria were having an important cognitive impairment or having an acute medical event that interfered with the activity. This process was carried out by the authors and by a group of interviewers.

The sample size required for construct validity and reliability according to Terwee is between 100 and 250 questionnaires, planned to be reached in one year[26].

Validation of understanding and feasibility

To evaluate feasibility and understanding, the instrument was tested as a pilot study on a small group of patients with the same characteristics indicated above, until saturation of the needed information was reached.

Every young person was asked to complete the questionnaire by herself/himself, measuring the time to do so. Once this was done, the questionnaires were reviewed item by item, asking them to explain what they understood in each question. Words that were not well understood were underlined, and the use of synonyms or a different way of asking the question was discussed with the participant for better understanding. Any difficulties with the scale were also considered and noted. Finally, they were asked about their general perception of the instrument.

Construct validity and reliability

The items that made up the questionnaire were grouped according to the different dimensions they theoretically measured. These dimensions were proposed by the authors considering what was learned from the instruments reviewed and confirmed by the experts' opinion.

The questionnaire was uploaded onto a Tablet using the *Teamscope* application (www.teamscope.co), which is a mobile research data collection app that allows data collection without an internet connection. Patients were then asked to respond by themselves on this device by giving them general instructions.

To confirm the validity of the instrument's construct, an exploratory factor analysis was performed, using Principal Component Analysis methodology[27], in order to detect the items with low communality. The remaining items were analyzed using the Kaiser-Meyer-Olkin test and Bartlett's Test of Sphericity[28], to evaluate if the data resulting from the previous

tests was adequate to perform the factor analysis. Based on Matsunaga's guidelines[29], the factor structure was determined and finally, the reliability was reviewed through the internal consistency of the components obtained from the previously described analyses.

Results

After reviewing the literature, we obtained the first version of the instrument with 6 domains: "daily activities" (3 items), "aspects of my illness" (4 items), "management and use of medications" (4 items initially), "practical aspects of health care" (6 items), "involvement in the health checkup" (4 items), and "transfer" (3 items).

Content validity

Within the I-CVI, 20 excellent and 3 good items were obtained. Item 2 "Do I do chores to help at home?" did not meet the necessary relevance criteria.

After evaluating the judges' qualitative suggestions, we decided to add an open-ended question for patients to leave their concerns. In addition, it was decided to separate into two questions an item which asked both if they knew the names of the medicines they used and what they were for (version no. 2, of 25 items plus an open question). The experts pointed out that the instrument could be used in patients aged between 12 and 18 years of age. They also commented on its usefulness in clinical care to prepare the transition or at the time of the first care in adult services. This could be done in the facility, waiting room or medical office, or via e-mail before the checkup. There were two suggestions to include a corresponding application of a modified instrument for parents.

After the advice of an external methodologist, the instrument was revised again and its wording was modified (version no. 3), temporarily maintaining the item that did not meet the experts' criteria, to assess its psychometric properties (Table 3). Then the response scale was included: *1) No, I don't need to; 2) No, but maybe I should; 3) I'll start doing it; 4) Yes, I started doing it recently; and 5) Yes, more than 6 months ago* (version no. 4).

Feasibility and understanding validity

Between June and July 2016, 8 patients aged from 12 to 16 were recruited for a pilot test. All of them agreed to participate. Among their pathologies were neurogenic bladder, renal transplant, anorectal malformation, type 1 diabetes, and major depression. All participants were able to answer version n°4 of the questionnaire, taking between 6 and 10 minutes. Afterward, their suggestions for word comprehension and writing were accepted, obtaining version n°5 of the questionnaire. The scale format had no suggestions for modifications.

Construct validity

Within one year, we did not reach the expected sample, so we managed to extend the study up to 2 years, period in which we recruited 174 patients who answered version n°5 of the questionnaire, mainly in the waiting room context. 168 (96%) of them completed it, thus 6 questionnaires were excluded from the analysis. The mean age was 14.4 years (SD = 1.66), with a median of 14 years (range 12-19). 66% were females.

In total, the patients were being treated by 21 clinical departments (Oncology, Pulmonary, Plastic Surgery, Endocrinology, Nephrology, Immunology, and Gastroenterology, among others). The most frequently reported conditions were asthma, type 1 diabetes, cleft lip, liver transplant, treated cancer in the follow-up stage, and chronic kidney disease.

Table 3 shows the mean and standard deviation for each item, as well as the internal consistency of each of the instrument dimensions.

To establish the instrument's factor structure, exploratory factor analysis was performed[30]. Since the data violated the multivariate normal distribution assumption, we used the principal axis factor analysis method to extract the factors on the 25 items that make up the questionnaire, using the sample of 168 subjects[31]. The inspection of the correlation matrix indicated that certain items did not have any correlation coefficient above +/- 0.3, so these items were removed and the Principal Component Analysis was executed again[27,32], resulting in 7 iterations, eliminating items 1, 2, 7, 10, 11, 17, 18, 23, 24, 25. With the remaining items, 6 consecutive factor extractions were performed, discarding one item per iteration, using as a criterion a saturation lower than 0.4[27]. This reduced the total to 9 items (3, 4, 5, 6, 8, 9, 15, 16, 20). The correlation matrix indicated that all variables had at least one correlation over 0.3. The overall Kaiser-Meyer-Olkin (KMO) measure was 0.75 with individual measures of KMO 0.7 except item 3 that obtained a value of 0.67. The rest of the indexes classify as 'regular' to 'meritorious'[28]. Bartlett's test of sphericity was statistically significant ($p < 0.0005$), indicating that the data is probably factorizable.

To determine the factor structure, a parallel analysis was performed following the guidelines established by Matsunaga[29], showing two components that account for 31.2% and 17.6% of the total variance, respectively. Together, the two-component solution represents 48.8% of the total variance. To facilitate interpre-

Table 3. Mean and Standar Deviation (DS) per item and internal consistency for each dimension

Dimension	Item	Mean ± DS	Cronbach's Alpha
Daily Activities	1. Do you take care of your own chores? (Organizing your room, homework, etc.)	4.31 ± 0.92	0.382
	2. Do I do chores to help at home? (setting the table, cooking, cleaning, etc.)*	4.22 ± 1.03	
	3. Do you go by yourself to shops, convenience stores, drugstores or others?°	4.02 ± 1.34	
Aspects of my illness	4. Do you know your medical history? (Diagnosis, procedures, hospitalizations, allergies)°	4.62 ± 0.86	0.537
	5. Do you know the characteristics of your illness? (Symptoms, prognosis, limitations)°	4.56 ± 0.91	
	6. Do you understand what caused your illness?	3.95 ± 1.32	
	7. Do you manage the basic care of your illness by yourself?	3.60 ± 1.42	
Management and use of medications	8. Do you know the name of your medicines, regular treatments or procedures?°	4.20 ± 1.23	0.702
	9. Do you know what your medicines, treatments or procedures are for?°	4.35 ± 1.12	
	10. Do you understand the side effects of your medicines? (Other effects they could give you, for example: stomach aches, kidney problems, high blood pressure)	3.19 ± 1.50	
	11. Do you correctly take or use your medicines, treatments or procedures by yourself?°	4.01 ± 1.34	
	12. Do you let someone know if you are running out of medicine or supplies?	3.63 ± 1.52	
Practical aspects of health care	13. Do you know what to do if you are not feeling well or get sick?	4.11 ± 1.33	0.649
	14. Do you know who to contact in case of emergency?	4.67 ± 0.85	
	15. Do you take care of booking your medical appointments?°	2.20 ± 1.21	
	16. Would you know how to get to the hospital by yourself?°	4.10 ± 1.33	
	17. Do you keep your own system to record/remember your medical appointments?	3.23 ± 1.53	
	18. Do you know which health insurance do you have and what does it cover?	3.35 ± 1.51	
Involvement in the health checkup	19. Are you the one who answers the doctor's or health professional's questions?	3.65 ± 1.21	0.665
	20. Would you be able to attend to the doctor's or health professional's checkup by yourself?°	3.39 ± 1.41	
	21. Do you actively talk to the doctor or other health professional? For example, by making questions, or telling them how you feel?	3.24 ± 1.47	
	22. Do you take part in the decisions taken regarding your health?	3.67 ± 1.39	
Transfer	23. Do you know when and where will you be transferred when you move into adult health services?	2.83 ± 1.36	0.452
	24. Do you keep medical records or do you have a summary of your medical history?	3.23 ± 1.48	
	25. Dou you feel ready to be transferred to adult health services?	2.49 ± 1.21	
Open question	26. If you like, you can leave your comments (questions, requests, or worries)		

*Insufficient relevance according to judges. °Acceptable psychometric results.

tability, we used an oblique rotation with the oblimin method.

When analyzing the two components thematically according to the items that showed greater communality, Component 1 involves items related to "Aspects of my Illness" and "Management and Use of Medications", while Component 2 includes "Practical Aspects of Health Care", "Involvement in the Health Checkup", and "Daily Activities". Table 4 includes the factor loads of saturation along with the communality of the rotated solution. The internal consistency of both components was reviewed, resulting in Component 1 Cronbach's alpha $\alpha = 0.68$ and Component 2 Cronbach's alpha $\alpha = 0.66$. These indicate reliability just bellow the acceptable minimum (weak level).

Open-ended question

Only 18 of the 174 participants used this segment. The low number of responses and the fact that most of them were very brief does not allow for an in-depth analysis.

The following are the comments received:

3 participants used it to express having had a bad experience in an adult hospital care (2 due to difficul-

Table 4. Rotated structural matrix for PAF (Principal Axis Factor), with Oblimin oblique rotation on a two component questionnaire

Items	Components of the rotated solution		
	Component 1	Component 2	Communality
5. Do you know the characteristics of your illness?	**0.71***	-0.093	0.476
9. Do you know what your medicines, treatments or procedures are for?	**0.580***	0.097	0.377
8. Do you know the name of your medicines, regular treatments, or procedures?	**0.543***	0.231	0.419
4. Do you know your medical history?	**0.518***	0.003	0.269
6. Do you understand what caused your illness?	**0.412***	-0.057	0.160
16. Would you know how to get to the hospital by yourself?	0.204	**0.679***	0.579
20. Would you be able to attend by yourself to the doctor's or health professional's checkup?	0.018	**0.609***	0.377
15. Do you take care of booking your medical appointments?	-0.027	**0.585***	0.334
3. Do you go by yourself to shops, convenience stores, drugstores, or others?	-0.052	**0.407***	0.157

* Loadings over 0.4 per item.

ty in getting an appointment and 1 due to inadequate care); 3 expressed the desire to extend the pediatric care beyond 15 years of age (until 17, until 18 and to never transfer); 3 proposed a change in the modality of responses in the questionnaire (to dichotomous yes/no answers, incorporating into the response scale an "I'm not allowed", and to change the scale into open answers); 2 gave congratulations for the questionnaire; 2 reported not knowing their final diagnosis; 1 asked how the questionnaire would help with the transfer to adult care; 1 expressed concern about the change of medical team due to the transfer; 1 expressed constant concern about her/his health; 1 asked at what age is the transfer, and 1 wrote an informal greeting.

Final instrument

A questionnaire was created with 6 dimensions and 24 items with their definitive numbering. Due to the scarce use of the open-ended question and to make the instrument easier to apply, it was not included. The 9 questions that had minimally acceptable psychometric tests are highlighted in the final instrument (Figure 1).

Discussion

In Chile, there is no universal policy of transition to adult care, there are only some local efforts to incorporate systematic preparation for this process. During the development of this research, the "*Programa Nacional de Salud Integral de Adolescentes y Jóvenes: Nivel Especializado de Atención Abierta y Cerrada*" was published[33], where, for the first time, there were ministerial recommendations to address the transition, adding to what had already been done in other countries. The program mentions different activities needed to prepare this process, including having instruments to evaluate adolescents with chronic illnesses during this stage, which is the focus of this research.

In this study, we were able to create an instrument with a set of items properly validated in its content by experts. We were able to establish that 9 of them meet the minimum criteria of psychometric reliability. However, keeping only those items would have meant eliminating questions of high clinical relevance. Therefore, we decided to keep the 24 items, but to highlight those with better reliability in the analyses of construct validity.

Based on our analyses, we recommend that researchers, interested in continuing to explore the properties and characteristics of the instrument, consider that there may have been difficulties in reading comprehension of the population evaluated and/or in keeping attention when facing a large number of items. Responding in the waiting room with high environmental interference may also have played a role, unlike the context of the pilot test.

In contrast to checklist surveys found in hospital programs, the graded scale allows for nuances beyond "achieved" or "not achieved", which allows a more detailed follow up of the patient when applying the test longitudinally. Even more so, considering that the scale based on the trans-theoretical model of change makes it possible to assess and work on the disposition to change health behaviors[25]. However, while this can be considered an advantage, it is also possible that the complexity of the scale could have contributed to the poor psychometric performance of the questions.

Folio/nombre:	Fecha de Nacimiento / /	Fecha hoy: / /
Sexo:		Edad:
Especialidad en dónde te atiendes:		
Diagnóstico(s) Principales:		

	1	2	3	4	5
ACTIVIDADES COTIDIANAS	No, no lo necesito	No, pero tal vez debiera	Empezaré a hacerlo	Sí, empecé a hacerlo hace poco	Sí, hace más de 6 meses
1. ¿Te responsabilizas de tus cosas personales? (Ordenar tu pieza, tareas escolares, etc.).					
2. ¿Vas a comprar tú solo a tiendas, almacenes, farmacias u otros lugares?*					
SUBTOTAL					

ASPECTOS DE MI ENFERMEDAD	No, no lo necesito	No, pero tal vez debiera	Empezaré a hacerlo	Sí, empecé a hacerlo hace poco	Sí, hace más de 6 meses
3. ¿Conoces tu historia médica? (Tus diagnósticos, si te han operado, hospitalizaciones, alergias).*					
4. ¿Sabes bien de qué se trata tu enfermedad? (Síntomas, pronostico y en qué te limita esta)*					
5. ¿Entiendes lo que causó tu enfermedad?*					
6. ¿Realizas tú sólo el cuidado básico de tu enfermedad?					
SUBTOTAL					

MANEJO Y USO DE MEDICAMENTOS	No, no lo necesito	No, pero tal vez debiera	Empezaré a hacerlo	Sí, empecé a hacerlo hace poco	Sí, hace más de 6 meses
7. ¿Conoces el nombre de los medicamentos, tratamientos o procedimientos que usas?*					
8. ¿Conoces para qué sirven los medicamentos, tratamientos o procedimientos que usas?*					
9. ¿Entiendes los efectos secundarios de los medicamentos que usas?(Otros efectos que te pueda provocar, por ejemplo: dolor de estómago, problemas a los riñones, subir la presión)					
10. ¿Usas/tomas tus medicamentos, tratamientos o procedimientos por ti mismo de forma correcta?*					
11. ¿Te preocupas de avisar cuando te quedan pocos medicamentos, dosis u otros materiales?					
SUBTOTAL					

ASPECTOS PRÁCTICOS DE LA ATENCIÓN DE SALUD	No, no lo necesito	No, pero tal vez debiera	Empezaré a hacerlo	Sí, empecé a hacerlo hace poco	Sí, hace más de 6 meses
12. ¿Sabes lo que debes hacer si te descompensas, te sientes mal o te enfermas?					
13. ¿Sabes a quién contactar en caso de emergencia?					
14. ¿Te encargas tú de pedir tus horas médicas?*					
15. ¿Sabrías cómo llegar por ti mismo al hospital?*					
16. ¿Tienes un sistema propio de registro y/o recordatorio de tus horas médicas?					
17. ¿Sabes cuál es tu plan de FONASA/ISAPRE u otro plan de salud y lo que este cubre?					
SUBTOTAL					

PARTICIPACIÓN EN LA CONSULTA	No, no lo necesito	No, pero tal vez debiera	Empezaré a hacerlo	Sí, empecé a hacerlo hace poco	Sí, hace más de 6 meses
18. ¿Eres tú el que responde las preguntas que hace el médico o profesional de salud?					
19. ¿Serías capaz de entrar tú solo, o sea sin tus padres, a la consulta del doctor u otro profesional de la salud?*					
20. ¿Te diriges al médico u otro profesional de la salud por tu propio interés, por ejemplo haciendo preguntas o contándoles lo que te pasa o cómo te sientes?					
21. ¿Participas en la toma de decisiones con respecto a tu salud?					
SUBTOTAL					

TRASLADO	No, no lo necesito	No, pero tal vez debiera	Empezaré a hacerlo	Sí, empecé a hacerlo hace poco	Sí, hace más de 6 meses
22. ¿Sabes a dónde y cuándo te trasladarán en el momento en que pases al sistema de salud adulto?					
23. ¿Tienes un registro de tu historia médica y/o resumen para el traslado?					
24. ¿Te sientes listo para ser trasladado al sistema de salud adulto?					
SUBTOTAL					

TOTAL	

Figure 1. State assessment questionnaire for transition. * Items that meet the minimum criteria of psychometric reliability.

Specifically, the differences with the results obtained in the TRAQ-5 questionnaire[15] as well as its Argentinean translation[14], could be explained because both instruments were validated in a group of older patients, 16 to 26 years old in the first one, and older than 14 years old in the second one[15], which would have a limited utility for the Chilean health context, where the transfer happens at the age of 15.

The validation of an instrument is a continuous and dynamic process that acquires more relevance as more psychometric properties have been measured in different cultures, with different populations, and subjects.

Despite the limitations raised, we believe that this work contributes to the first steps in the development of an instrument adapted to to our local reality, obtaining a set of questions of clinical relevance, validated by experts, and clinically useful for proffesionals helping patients prepare their transition. Although in general terms the instrument has significant problems regarding psychometric reliability, this study presents detailed information about its properties, complementing the research carried out to date[13]. We also see as an advantage the fact that it is directed at patients with chronic conditions in general, since it allows covering a wide range of pathologies, and its self-reporting format simplifies its implementation. This research allows us to establish the first steps towards finding variables that may be clinically relevant for the prediction of success in the transition.

The clinical work in transition should be focused on the needs of the patient[9-12], and this instrument offers a way to visualize important elements for patients during this transition. Although this instrument did not achieve methodological validation, it contains elements that, according to our clinical experience, are useful to apply in clinical departments, or directly administering it to adolescents in the healthcare setting. To get to know the stage of the process our patient is at and the areas that need strengthening. Therefore, it could be used by the clinical teams as an evaluation-intervention instrument, considering the limitations that the lack of validation implies.

In conclusion, the analysis allowed us to build a self-report questionnaire to measure the state of preparation of adolescents for transition, based on international questionnaires, with content validated by local experts, and feasible to apply in a limited time. We reported the psychometric properties of the instrument, proving the validity of the construct and reliability for 9 of the 24 items, which represents an insufficient validation. This should be considered at the time of its application in the clinical practice.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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References

1. Vargas N, Quezada A. Epidemiología, nueva morbilidad pediátrica y rol del pediatra. Rev Chil Pediatr. 2007;78(1):103-10.
2. Huang JS, Gottschalk M, Pian M, Dillon L, Barajas D, Bartholomew LK. Transition to adult care: systematic assessment of adolescents with chronic illnesses and their medical teams. J Pediatr. 2011;159(6):994-8.
3. Inostroza C, Correa ML, Besoaín C, et al. El proceso de transición de servicios pediátricos a adultos: visión de adolescentes hospitalizados portadores de enfermedades crónicas. Rev Chil Pediatr. 2016;87(2):110-5.
4. Pacaud D, Yale JF, Stephure D, Truselle R, Davies HD. Problems in Transition From Pediatric Care to Adult Care for Individuals With Diabetes. Canadian journal of Diabetes. 2005;29(1):13-8.
5. Lam PY, Fitzgerald BB, Sawyer SM. Young adults in children's hospitals: why are they there?. Med J Aust. 2005;182(8):381-4.
6. Geerts E, van de Wiel H, Tamminga R. A pilot study on the effects of the transition of paediatric to adult health care in patients with haemophilia and in their parents: patient and parent worries, parental illness-related distress and health-related Quality of Life. Haemophilia. 2008;14(5):1007-13.
7. Wolf-Branigin M, Schuyler V, White P. Improving quality of life and career readiness of adolescents with disabilities: experiences from the Adolescent Employment Readiness Center. Res Soc Work Pract. 2007;17(3):324-33.
8. Gaete V, Henríquez ME, Robledo P, et al. Fundamentos para la extensión de la edad pediátrica hasta el término de la adolescencia a nivel de toda la red asistencial de salud. Recomendación del Comité de Adolescencia de la Sociedad Chilena de Pediatría. Rev Chil Pediatr. 2011;82(5):447-53.
9. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A Consensus statement on health care transitions for young adults with special health care needs. Pediatrics. 2002;110:1304-6.
10. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley W C, Sagerman P J. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics. 2011;128(1):182-200.
11. Lizama M, Ávalos M, Vargas N, Varela M, Navarrete C, Galanti M, Orellana J. Transición al cuidado de la vida adulta, de niños y adolescentes con necesidades especiales de atención en salud: recomendaciones del comité NANEAS de la Sociedad Chilena de Pediatría. Rev Chil Pediatr. 2011;82(3):238-44.
12. Zubarew T, Correa L, Bedregal P, et al. Transición de adolescentes portadores de enfermedades crónicas desde servicios pediátricos a servicios de adultos. Recomendaciones de la Rama de Adolescencia de la Sociedad Chilena de Pediatría. Rev Chil Pediatr. 2017; 88(4):553-60. DOI: 10.4067/S0370-41062017000400018.
13. Zhang L, Ho J, Kennedy S. A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. BMC Pediatrics. 2014; 14: 4.
14. González F, Roizen M, Rodríguez M, et al. Validación español-argentina del cuestionario de transición a la atención médica del adulto en adolescentes con enfermedades crónicas. Arch Argent Pediatr 2017;115(1):18-27/18.
15. Wood DL, Sawicki GS, Miller D, et al. The Transition Readiness Assessment Questionnaire (TRAQ): Its Factor Structure, Reliability, and Validity. Academic Pediatrics. 2014;14:415-22.
16. Ferris M, Harward D, Bickford K, et al. A clinical tool to measure the components of health- care transition from pediatric care to adult care: the UNC TR(x) ANSITION scale. Ren Fail. 2012;34:744-53.
17. Williams T, Sherman E, Dunseith C, et al. Measurement of medical self-management and transition readiness among Canadian adolescents with special health care needs. Int J Child Adolesc Health. 2010;3:527-35.
18. Klassen AF, Grant C, Barr R, et al. Development and validation of a generic scale for use in transition programmes to measure self-management skills in adolescents with chronic health conditions: the TRANSITION-Q. Child Care Health Dev. 2015;41(4):547-58.
19. Patton SR, Graham JL, Varlotta L, Holsclaw D. Measuring self-care independence in children with cystic fibrosis: the self-care independence scale (SCIS). Pediatr Pulmonol. 2003; 36:123-30.
20. Gilleland J, Amaral S, Mee L, Blount R. Getting ready to leave: transition readiness in adolescent kidney transplant recipients. J Pediatr Psychol. 2012;37:85-96.
21. Fredericks EM, Dore-Stites D, Well A, et al. Assessment of transition readiness skills and adherence in pediatric liver transplant recipients. Pediatric Transplant. 2010;14:944-953.
22. Grant JS, Davis LL. Selection and use of content experts for instrument development. Research in Nursing & Health. 1997;20(3):269-74.
23. Davis LL. Instrument review: Getting the most from a panel of experts. Applied Nursing Research. 1992;5(4):194-7.
24. Polit DF, Beck CT, Owen SV. Is the CVI an Acceptable Indicator of Content Validity? Appraisal and Recommendations. Research in Nursing & Health. 2007;30:459-67.
25. Prochaska JO. Decision making in the transtheoretical model of behavior change. Medical Decision Making. 2008;28(6):845-9.
26. Terwee CB, Bot SD, de Boer MR,et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol. 2007;60(1):34-42.
27. Gie Yong A, Pearce S. A Beginner's Guide to Factor Analysis: Focusing on Exploratory Factor Analysis. Tutorials in Quantitative Methods for Psychology. 2013;9(2):79-94.
28. Kaiser HF. An index of factorial simplicity. Psychometrika. 1974;39:32-6.
29. Matsunaga M. How to factor-analyze your data right: Do's, don'ts, and how-to's. International Journal of Psychological Research. 2010;3(1):97-110.
30. Flora DB, Flake JK. The purpose and practice of exploratory and confirmatory factor analysis in psychological research: Decisions for scale development and validation. Canadian Journal of Behavioural Science 2017;49(2):78-88.
31. Fabrigar LR, Wegener DT, Maccallum RC, Strahan EJ. Evaluating the Use of Exploratory Factor Analysis in Psychological Research. Psychological Methods. 1999;4(3):272-99.
32. Lloret-Segura S, Ferreres-Traver A, Hernández-Baeza A, Tomás-Marco I. (2014). El Análisis Factorial Exploratorio de los Ítems: una guía práctica, revisada y actualizada. Anales de Psicología. 2014;30(3):1151-69.
33. MINSAL 2018. Programa nacional de salud integral de adolescentes y jóvenes: nivel especializado de atención abierta y cerrada. Disponible en: https://diprece.minsal.cl/wp-content/uploads/2018/12/2018.12.13_PROGRAMA-ADOLESCENTES_web.pdf.