




The cultural differences in transition assessment: Evaluation of TRANSITION-Q and STARx scales on Turkish rheumatic patients

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ABSTRACT

Objectives: This study aimed to assess the readiness of our patient population for the transfer to adult care and the applicability of the TRANSITION-Q and STARx scales to the Turkish adolescent patient population.

Patients and methods: A total of 153 patients (92 males, 61 females; mean age: 15.5±1.9 years; range, 12 to 18 years) were included in the study between September 15, 2021, and December 15, 2021. The patients were divided into two groups according to age groups: 12 to 15 years old and 16 to 18 years old. The patients were also divided into four groups according to their diagnosis: connective tissue diseases, juvenile idiopathic arthritis, vasculitis, and autoinflammatory diseases. The TRANSITION-Q and STARx scales were administered face-to-face by a nurse and a doctor. The transition readiness of the patients was evaluated according to their scores.

Results: Sixty-nine (45%) patients were in the 12 to 15 age group, and 84 (55%) were in the 16 to 18 age group. Eight-four (54.9%) patients had juvenile idiopathic arthritis, 47 (30.7%) patients had an autoinflammatory disease, 14 (9.2%) patients had vasculitis, and eight (5.2%) patients had a connective tissue disease. There was no significant difference in the scale scores according to disease groups and sexes in both scales. Considering the age of the patients, the mean scores of the patients in the 16 to 18 age group were found to be significantly higher compared to the 12 to 15 age group for both the TRANSITION-Q (74.3±13.3 vs. 65.4±9.6, $p<0.001$) and STARx scales (51.8±8.1 vs. 44.8±9.1, $p<0.001$). Cronbach's alpha score was 0.71 for the STARx scale and 0.79 for the TRANSITION-Q scale.

Conclusion: TRANSITION-Q and STARx scales could guide the Turkish patient population in determining the pretransition needs of patients in planning individualized transition processes.

Keywords: Pediatric rheumatology, transition care, TRANSITION-Q, STARx.

Transitional care delineates the systematic progression of adolescents enduring chronic physical and medical ailments from pediatric healthcare paradigms to adult-oriented healthcare frameworks, characterized by deliberate and well-structured planning.¹ This terminology entered the medical literature approximately 35 years ago,² finding its way into rheumatology discourse after about a decade.³ In recent years, there has been a notable uptick in the number of patients migrating from pediatric rheumatology clinics to adult counterparts, a trend fueled by advancements in patient management and diagnostic procedures.^{4,5} Hence, the implementation of efficacious transitional care protocols has emerged as a vital component within pediatric rheumatology clinical follow-up routines.

Childhood-onset rheumatic diseases, including juvenile idiopathic arthritis (JIA), juvenile systemic lupus erythematosus, juvenile dermatomyositis, and familial Mediterranean fever, harbor the potential to significantly impair health and life quality into adulthood. Transitional adversities encountered by individuals with chronic ailments invariably exert negative repercussions on cardiovascular well-being, growth trajectories, and fertility prospects.

In response, a series of validated transition scales have been developed. Crucially, these incorporate scales dedicated to gauging the transitional readiness of adolescents, facilitating the identification of potential inadequacies and thus enabling clinicians to concentrate their efforts

accordingly. Noteworthy examples of these scales encompass the Transition Readiness Assessment Questionnaire (TRAQ),⁶ the TRxANSITION Index,⁷ the STARx (Self-Management and Transition to Adulthood with Rx: Treatment) scale,⁸ the Am I ON TRAC for Adult Care scale,⁹ the TRANSITION-Q,¹⁰ and the Adolescent Assessment of Preparation for Transition.¹¹ It is imperative that these scales retain clinical relevance and conform to stringent psychometric evaluations.

In light of prevalent cultural disparities, it becomes imperative to scrutinize the suitability of scale questions across different global populations. Regrettably, scholarly endeavors in this regard remain scant at present. This study seeks to bridge this existing research gap. We endeavor to evaluate not only the readiness of our patient demographic for transitioning to adult healthcare facilities but also the feasibility of applying these scales within the context of the Turkish adolescent patient population.

PATIENTS AND METHODS

The cross-sectional study included 153 patients (92 males, 61 females; mean age: 15.5±1.9 years; range, 12 to 18 years) who sought medical attention at the pediatric rheumatology clinic of the Umraniye Training and Research Hospital from September 15, 2021, to December 15, 2021. A collaborative assessment employing the TRANSITION-Q and STARx scales was conducted through face-to-face interviews with medical professionals, encompassing a nurse and a doctor. The participant cohort was divided into two age groups: 12 to 15 years and 16 to 18 years. Furthermore, they were classified into four distinct categories based on their diagnoses: connective tissue diseases (CTDs), JIA, vasculitis, and autoinflammatory diseases (AIDs). Clarifications were provided for queries that were not comprehended by the patients. The questions were clarified in a manner that did not create bias, and no leading was implemented.

The TRANSITION-Q scale, comprising 14 questions, was conceived utilizing a modern psychometric approach predicated on the Rasch model at the McMaster Children's Hospital in Canada.¹ The instrument evaluates individuals'

proficiency in managing their medical care, their interactions with healthcare professionals, chronic disease awareness, and their competency in undertaking technical responsibilities, such as organizing appointments and managing prescriptions. Participants articulate their responses utilizing a scale ranging from "never" to "always," which correspond to scores between 0 and 2. The cumulative scores vary from 0 to 100, where elevated scores are indicative of proficient self-management skills. The maximal attainable score is 100, with the Canadian study reporting a Cronbach alpha value of 0.85 for this scale.¹ Based on the scores accrued, the preparedness for transition is ascertained. No upper threshold exists, delineating a lack of readiness for transition. This facilitates the identification of participants' strengths and weaknesses throughout the transitional preparedness phase, enabling targeted intervention to rectify identified inadequacies. The requisite license for the TRANSITION-Q was procured from McMaster University.

The STARx scale, originating from the University of North Carolina at Chapel Hill School of Medicine, was devised to assimilate data on self-management and transition in adolescents grappling with chronic illnesses.² It encompasses 18 items distributed across six focal areas, assessing the patients' readiness for transition. These domains comprise medical treatment management, communication with physicians, collaborative engagement during consultations, adult health responsibilities, resource utilization, and disease knowledge. Each item is scored on a 5-point Likert scale, culminating in a maximum potential score of 90. A higher score is synonymous with an advanced stage of readiness for transition. The original study documenting the scale's development reported a Cronbach alpha value of 0.8.²

The translation of the TRANSITION-Q and STARx surveys into Turkish was conducted by two researchers. Both researchers possessed advanced level proficiency in English. Professional assistance was not sought.

Statistical analysis

The data were analyzed utilizing IBM SPSS version 21.0 software (IBM Corp., Armonk, NY, USA). The validity of the Turkish versions of the TRANSITION-Q and STARx scales was

ascertained through the assessment of internal consistency, demonstrated by Cronbach's alpha coefficient, and test-retest reliability, as delineated by the intraclass correlation coefficient. The Cronbach's alpha values were interpreted as follows: <0.5, unacceptable; 0.5 to 0.59, poor; 0.6 to 0.69, questionable; 0.7 to 0.79, acceptable; 0.8 to 0.89, good; 0.9 to 1.0, excellent. Categorical variables were expressed as frequencies and percentages, whereas continuous variables were articulated as mean \pm standard deviation or median (interquartile range), as per their distribution. Comparative analyses between groups were conducted using Student's t-test or one-way analysis of variance. Logistic regression analysis facilitated the identification of predictors for high and low scores. A p-value <0.05 was established as the threshold for statistical significance.

RESULTS

The mean follow-up duration and disease duration were 2.71 ± 1.31 years and 4.63 ± 3.48 years, respectively. The onset of disease manifested at a mean age of 10.71 ± 3.88 years. Sixty-nine (45%) patients fell within the 12 to 15 years category, and 84 (55%) were classified under the 16 to 18 years group.

Diagnostically, patients were clustered into four categories: 84 (54.9%) were diagnosed with JIA, 47 (30.7%) had AID, 14 (9.2%) manifested vasculitis, and eight (5.2%) had a CTD. Of these, 61 (39.9%) were prescribed biological disease-modifying antirheumatic drugs (DMARDs), while 92 (60.1%) were either on conventional DMARDs or were undergoing drug-free monitoring.

The mean score derived from the TRANSITION-Q scale was 70.3 ± 12.6 . No discernible differences were noted between sexes or amongst distinct disease groups in relation to

the TRANSITION-Q score (Table 1). Moreover, no significant disparity was observed between scores of patients administered biological DMARDs and their counterparts. Notably, patients within the age bracket of 16 to 18 years scored significantly higher compared to those aged 12 to 15 years, with mean scores of 74.3 ± 13.3 and 65.4 ± 9.6 , respectively, indicating a p-value of <0.001 (Table 1). Most patients consistently responded with "always" to Item 7 (I ask the doctor or nurse questions; 96%) and to Item 1 (I answer a doctor's or nurse's questions; 92%). Conversely, Item 12 (I drop off or pick up my prescriptions when I need medicine) garnered the least number of "always" responses (12%; Tables 2 and 3). The Turkish translation of the scale, as administered to our cohort, demonstrated a promising Cronbach's alpha coefficient of 0.79.

The mean score registered on the STARx scale was 48.6 ± 9.3 . Similar to the TRANSITION-Q findings, no significant sex disparity was observed, nor were there notable differences between disease groups and the STARx score (Table 1). Furthermore, no considerable variations were noted between scores upon examination of drug groups. A noteworthy observation was that the STARx scores for patients aged 16 to 18 years superseded those of patients aged 12 to 15 years, with respective mean scores of 51.8 ± 8.1 and 44.8 ± 9.1 and a significant p-value of <0.001 (Table 1). An analysis of responses to individual questions revealed a predominant selection of "sometimes" for queries related to medical treatment management (Questions 2, 5, 8, and 16), with a mean score of 9.4 ± 2.1 . The questions revolving around adult health responsibilities (Questions 17 and 18) received the lowest scores, with a mean of 4.9 ± 2.1 . Patients mostly reported feeling "somewhat difficult" when addressing concerns related to appointment scheduling, prescription adherence, medication monitoring,

Table 1. Mean scores of TRANSITION-Q and STARx scales by diseases and age groups

	JIA (n=84)	AID (n=47)	Vasculitis (n=14)	CTD (n=8)		Ages 12-15 (n=69)	Ages 16-18 (n=84)	
	Mean \pm SD	Mean \pm SD	Mean \pm SD	Mean \pm SD	p	Mean \pm SD	Mean \pm SD	p
TQ score	69.8 \pm 11.7	70.5 \pm 13.2	69.6 \pm 13.8	74.6.5 \pm 16.9	0.75	65.4 \pm 9.6	74.3 \pm 13.3	<0.001
STARx score	48.8 \pm 9.2	48.4 \pm 10.1	49 \pm 8.7	48.6 \pm 9.3	0.974	44.8 \pm 9.4	51.8 \pm 8.1	<0.001

TQ: TRANSITION-Q; STARx: Self-management and transition to adulthood with Rx: Treatment; JIA: Juvenile idiopathic arthritis; AID: Autoinflammatory Diseases; CTD: Connective tissue diseases; SD: Standard deviation.

Table 2. Results of TRANSITION-Q items by disease groups

	JIA (n=84)		AID (n=47)		Vasculitis (n=14)		CTD (n=8)	
	n	%	n	%	n	%	n	%
TRQ1								
I answer a doctor's or nurse's questions								
Never	0	0	0	0	0	0	0	0
Sometimes	10	11.9	2	4.3	0	0	0	0
Always	74	88.1	45	95.7	14	100	8	100
TRQ2								
I help to make decisions about my health								
Never	1	1.2	0	0	0	0	0	0
Sometimes	15	17.9	9	19.1	4	28.6	0	0
Always	68	81	38	80.9	10	71.4	8	100
TRQ3								
I am in charge of taking any medicine that I need								
Never	3	3.6	1	2.1	0	0	0	0
Sometimes	14	16.7	10	21.3	5	35.7	0	0
Always	67	79.8	36	76.6	9	64.3	8	100
TRQ4								
I talk to a doctor or nurse when I have health concerns								
Never	4	4.8	2	4.3	0	0	0	0
Sometimes	19	16.7	10	21.3	5	35.7	3	37.5
Always	61	72.6	35	74.5	9	64.3	5	62.5
TRQ5								
I look for an answer when I have a question about my health								
Never	0	0	1	2.1	0	0	0	0
Sometimes	18	21.4	11	23.4	4	28.6	1	12.5
Always	66	78.6	35	74.5	100	71.4	7	87.5
TRQ6								
I talk about my health condition to people when I need to								
Never	8	9.5	3	6.4	2	14.3	0	0
Sometimes	47	56	16	34	7	50	3	37.5
Always	29	78.6	28	59.6	5	35.7	5	62.5
TRQ7								
I ask the doctor or nurse questions								
Never	0	0	0	0	0	0	0	0
Sometimes	3	3.6	3	6.4	0	0	0	0
Always	81	96.4	44	93.6	14	100	8	100
TRQ8								
I speak to the doctor instead of my parent(s) speaking for me								
Never	2	2.4	2	4.3	0	0	0	0
Sometimes	34	40.5	17	36.2	7	50	4	50
Always	48	57.1	28	59.6	7	50	4	50
TRQ9								
I summarize my medical history when I am asked to								
Never	3	3.6	2	4.3	2	14.3	0	0
Sometimes	33	39.3	16	34	4	28.6	3	37.5
Always	48	57.1	29	61.7	8	67.1	5	62.5
TRQ10								
I contact a doctor when I need to								
Never	6	7.1	7	14.9	2	14.3	1	12.5
Sometimes	52	61.9	24	51.1	7	50	4	50
Always	26	31	16	34	5	35.7	3	37.5
TRQ11								
I see the doctor or nurse on my own during an appointment								
Never	2	2.4	1	2.1	0	0	0	0
Sometimes	29	34.5	15	31.9	1	7.1	4	50
Always	53	63.1	31	66	13	92.9	4	50
TRQ12								
I drop off or pick up my prescriptions when I need medicine								
Never	32	48.9	23	48.9	5	35.7	4	50
Sometimes	38	45.2	16	34	7	50	2	25
Always	14	16.7	8	17	2	14.3	2	25
TRQ13								
I travel on my own to a doctor's appointment								
Never	32	38.1	21	44.7	6	42.9	4	50
Sometimes	30	35.7	13	27.7	5	35.7	1	12.5
Always	22	26.2	13	27.7	3	21.4	3	37.5
TRQ14								
I book my own doctor's appointments								
Never	37	44	20	42.6	7	50	4	50
Sometimes	25	29.8	17	36.2	5	35.7	1	12.5
Always	22	26.2	10	21.3	2	14.3	3	37.5

JIA: Juvenile idiopathic arthritis; AID: Autoinflammatory diseases; CTD: Connective tissue diseases; TRQ: TRANSITION-Q.

Table 3. Results of TRANSITION-Q items by age groups

	Ages 12-15 (n=69)		Ages 16-18 (n=84)	
	n	%	n	%
TRQ1 I answer a doctor's or nurse's questions				
Never	0	0	0	0
Sometimes	6	8.7	6	7.1
Always	63	91.3	78	92.9
TRQ2 I help to make decisions about my health				
Never	1	1.4	0	0
Sometimes	14	20.3	14	16.7
Always	54	78.3	70	83.3
TRQ3 I am in charge of taking any medicine that I need				
Never	4	5.8	0	0
Sometimes	15	21.7	14	16.7
Always	50	72.5	70	83.3
TRQ4 I talk to a doctor or nurse when I have health concerns				
Never	2	2.9	4	4.8
Sometimes	18	26.1	19	22.6
Always	49	71	61	72.6
TRQ5 I look for an answer when I have a question about my health				
Never	1	1.4	0	0
Sometimes	23	33.3	11	13.1
Always	45	65.2	73	86.9
TRQ6 I talk about my health condition to people when I need to				
Never	8	11.6	5	6
Sometimes	35	50.7	38	45.2
Always	26	37.7	41	48.8
TRQ7 I ask the doctor or nurse questions				
Never	0	0	0	0
Sometimes	5	7.2	1	1.2
Always	64	92.8	83	98.8
TRQ8 I speak to the doctor instead of my parent(s) speaking for me				
Never	2	2.9	2	2.4
Sometimes	39	56.5	23	27.4
Always	28	40.6	59	70.2
TRQ9 I summarize my medical history when I am asked to				
Never	4	5.8	3	3.6
Sometimes	22	31.9	34	40.5
Always	43	62.3	47	56
TRQ10 I contact a doctor when I need to				
Never	7	10.1	9	10.7
Sometimes	51	73.9	36	42.9
Always	11	15.9	39	46.4
TRQ11 I see the doctor or nurse on my own during an appointment				
Never	2	2.9	1	1.2
Sometimes	26	37.7	22	26.2
Always	41	59.4	61	72.6
TRQ12 I drop off or pick up my prescriptions when I need medicine				
Never	42	60.9	22	26.2
Sometimes	23	33.3	40	47.6
Always	4	5.8	22	26.2
TRQ13 I travel on my own to a doctor's appointment				
Never	40	58	23	27.4
Sometimes	18	26.1	31	36.9
Always	11	15.9	30	35.7
TRQ14 I book my own doctor's appointments				
Never	44	63.8	24	28.6
Sometimes	17	24.6	31	36.9
Always	8	11.6	29	34.5

JIA: Juvenile idiopathic arthritis; AID: Autoinflammatory diseases; CTD: Connective tissue diseases; TRQ: TRANSITION-Q.

Table 4. Results of STARx questions by disease groups

	JIA (n=84)		AID (n=47)		Vasculitis (n=14)		CTD (n=8)	
	n	%	n	%	n	%	n	%
STARx1								
How often did you make an effort to understand what your doctor told you?								
Never	3	3.6	2	4.3	2	14.3	0	0
Almost never	5	6	1	2.1	1	7.1	1	12.5
Sometimes	7	8.3	8	17	1	7.1	1	12.5
Almost always	17	20.2	9	19.1	3	21.4	1	12.5
Always	52	61.9	27	57.4	7	50	5	62.5
STARx2								
How often did you take your medicines on your own?								
Never	7	8.3	1	2.1	0	0	0	0
Almost never	2	2.4	1	2.1	0	0	0	0
Sometimes	13	15.5	7	14.9	3	21.4	0	0
Almost always	13	15.5	12	25.5	4	28.6	1	12.5
Always	49	58.3	26	55.3	7	50	7	87.5
STARx3								
How often did you ask doctors or nurses questions about your illness, medicines or medical care?								
Never	4	4.8	5	10.6	0	0	0	0
Almost never	31	36.9	16	34	7	50	12	25
Sometimes	16	19	6	12.8	1	7.1	1	12.5
Almost always	24	28.6	16	34	5	35.7	4	50
Always								
STARx4								
How often did you make your own appointments?								
Never	26	31	18	38.3	4	28.6	3	37.5
Almost never	5	6	5	10.6	2	14.3	1	12.5
Sometimes	27	32.1	10	21.3	4	28.6	1	12.5
Almost always	5	6	5	10.6	0	0	0	0
Always	21	25	9	19.1	4	28.6	3	37.5
STARx5								
How often did you need someone to remind you to take your medicines?								
Never	15	17.9	8	17	2	14.3	2	25
Almost never	11	13.1	5	10.6	0	0	1	12.5
Sometimes	40	47.6	22	46.8	11	78.6	5	62.5
Almost always	11	13.1	6	12.8	1	7.1	0	0
Always	7	8.3	6	12.8	0	0	0	0
STARx6								
How often did you use things like pillboxes, schedules, or alarm to help you take their medicines when they were supposed to?								
Never	8	9.5	6	12.8	3	21.4	1	12.5
Almost never	20	23.8	5	10.6	4	28.6	1	12.5
Sometimes	2	2.4	2	4.3	1	7.1	1	12.5
Almost always	11	13.1	6	12.8	2	14.3	0	0
Always								
STARx7								
How often did you use the internet, books or other guides to find out more about his/her illness?								
Never	13	15.5	9	19.1	2	14.3	1	12.5
Almost never	8	9.5	5	10.6	0	0	0	0
Sometimes	31	36.9	19	40.4	5	35.7	4	50
Almost always	18	21.4	3	6.4	2	14.3	0	0
Always	14	16.7	11	23.4	5	35.7	3	37.5
STARx8								
How often did you forget to take your medicines?								
Never	12	14.3	2	4.3	3	21.4	3	37.5
Almost never	16	19	1	31.9	2	14.3	0	0
Sometimes	45	53.6	26	55.3	8	57.1	4	50
Almost always	5	6	2	4.3	1	7.1	1	12.5
Always	6	7.2	2	4.3	0	0	0	0
STARx9								
How often did you work with your doctor to take care of new health problems that came up?								
Never	4	4.8	6	12.8	0	0	0	0
Almost never	6	7.1	6	12.8	2	14.3	0	0
Sometimes	21	25	11	23.4	4	28.6	3	37.5
Almost always	21	25	7	14.9	4	28.6	0	0
Always	32	38.1	17	36.2	4	28.6	5	62.5
STARx10								
How much do you know about your illness?								
Nothing	1	1.2	0	0	0	0	0	0
Not much	1	1.2	0	0	0	0	0	0
A little	9	10.7	4	8.5	1	7.1	1	12.5
Some	36	42.9	21	44.7	8	57.1	3	37.5
A lot	37	44	22	46.8	5	35.7	4	50

Table 4. Continued

	JIA (n=84)		AID (n=47)		Vasculitis (n=14)		CTD (n=8)	
	n	%	n	%	n	%	n	%
STARx11								
How much does you know about taking care of your illness?								
Nothing	4	4.8	2	4.3	0	0	0	0
Not much	4	4.8	1	2.1	0	0	1	12.5
A little	14	16.7	5	10.6	2	14.3	0	0
Some	34	40.5	20	42.6	8	57.1	3	37.5
A lot	28	33.3	19	40.4	4	28.6	4	50
STARx12								
How much does you know about what will happen if you do not take your medicines?								
Nothing	3	3.6	1	2.1	2	14.3	0	0
Not much	3	3.6	2	4.3	1	7.1	0	0
A little	13	15.5	1	2.1	0	0	2	25
Some	25	29.8	15	31.9	7	50	2	25
A lot	40	47.6	28	59.6	4	28.6	4	50
STARx13								
How easy or hard is it for you to talk to your doctor?								
Very hard	5	6	1	2.1	0	0	0	0
Somewhat hard	9	10.7	10	21.3	2	14.3	2	25
Neither hard nor easy	15	17.9	1	2.1	3	21.4	1	12.5
Somewhat easy	15	17.9	12	25.5	3	21.4	0	0
Very easy	40	47.6	23	48.9	6	42.9	5	62.5
STARx14								
How easy or hard is it for you to make a plan with your doctor to care for your health?								
Very hard	3	3.6	1	2.1	0	0	0	0
Somewhat hard	11	13.1	6	12.8	1	7.1	1	12.5
Neither hard nor easy	19	22.6	12	25.5	3	21.4	4	50
Somewhat easy	18	21.4	8	17	5	35.7	0	0
Very easy	33	39.3	20	42.6	5	35.7	3	37.5
STARx15								
How easy or hard is it for you to see your doctor by yourself?								
Very hard	4	4.8	4	8.5	1	7.1	0	0
Somewhat hard	22	26.2	13	27.7	2	14.3	3	37.5
Neither hard nor easy	8	9.5	5	10.6	3	21.4	1	12.5
Somewhat easy	12	14.3	2	4.3	2	14.3	1	12.5
Very easy	38	45.2	23	48.9	6	42.9	3	37.5
STARx16								
How easy or hard is it for you to take your medicines the way they are supposed to?								
Very hard	5	6	0	0	0	0	0	0
Somewhat hard	17	20.2	10	21.3	4	28.6	2	25
Neither hard nor easy	14	16.7	6	12.8	5	35.7	2	25
Somewhat easy	11	13.1	11	23.4	1	7.1	2	25
Very easy	37	44.1	20	42.6	4	28.6	2	25
STARx17								
How easy or hard is it for you to take care of yourself?								
Very hard	3	3.6	0	0	0	0	0	0
Somewhat hard	13	15.5	9	19.1	2	14.3	3	37.5
Neither hard nor easy	15	17.9	7	14.9	2	14.3	1	12.5
Somewhat easy	14	16.7	12	25.5	7	50	3	37.5
Very easy	39	46.4	19	40.4	3	21.4	5	62.5
STARx18								
How easy or hard do you think it will be for you to move from pediatrics to adult-focused care?								
Very hard	13	15.5	7	14.9	0	0	1	12.5
Somewhat hard	16	19	13	27.7	5	35.7	4	50
Neither hard nor easy	24	28.6	8	17	3	21.4	3	37.5
Somewhat easy	13	15.5	1	2.1	1	7.1	0	0
Very easy	18	21.4	18	38.3	5	35.7	0	0

STARx: Self-management and transition to adulthood with Rx: Treatment; JIA: Juvenile idiopathic arthritis; AID: Autoinflammatory diseases; CTD: Connective tissue diseases.

and adapting to adult clinics. While responses to questions regarding doctor-nurse communication (Questions 13, 14, and 15) were generally favorable, indicating ease of communication, the group yielded a mean score of 8.4±3.1. The questions concerning disease information

(Questions 10, 11, and 12) received a mean score of 9.5±2.2, predominantly being rated as “a lot,” thus marking this set as having the highest mean score. Mutual negotiation during appointments (Questions 1, 3, and 4) had a mean score of 7.5±2.7, whereas resource utilization evaluation

(Questions 6, 7, and 9) received a mean score of 6.03 ± 2.8 (Table 4). The Turkish rendition of the STARx scale, when applied to our cohort, yielded a Cronbach's alpha coefficient of 0.71, indicating a satisfactory level of internal consistency.

DISCUSSION

Evaluating the readiness of patients for transitional care and heightening the awareness of transition mechanisms are paramount, necessitating tools and guidelines reinforced by empirical data. In our locale, however, tools for assessing adolescents with chronic diseases are rather scarce, with limited studies undertaken in this area.⁵

In the pursuit of alleviating the strain on the healthcare system, fostering a smooth transition from pediatric to adult rheumatology care for patients and their families stands as a crucial initial step. Recent investigations and guideline propositions advocate initiating the transition phase during early adolescence, typically around 10 to 13 years of age.^{3,12} This stance is echoed in the national directives of countries including the USA, Canada, and the UK.¹³⁻¹⁵

Although there has been a surge in awareness surrounding this issue in recent years, one study revealed that merely half of the patients were consulted regarding transition, and a nominal fraction could manage their ailments autonomously.¹⁶ The significance and recognition of transitional care are witnessing a global upswing,¹⁷ yet consensus remains elusive when it comes to determining suitable preparedness measures and tools for effective transition strategizing.

In the present study, we scrutinized two separate scales. A notable pattern emerged from both scales, highlighting that tasks necessitating personal responsibility, such as attending examinations alone or scheduling outpatient clinic appointments, were particularly challenging for patients. This aligns with the firsthand observations of pediatricians in Türkiye, where children predominantly attend clinical follow-ups accompanied by their parents, who also tend to oversee medication administration and monitoring. Contrary to Western norms, Turkish children

generally reside with their families well into adulthood, resulting in a family-centric approach to disease management, wherein the entire family shoulders the responsibility of medical treatment.

Supporting this notion, Aytaç et al.¹⁸ found family behaviors to be consonant with the prevailing cultural milieu. Similarly, a study by Suris et al.¹⁹ emphasized a heightened protective inclination among parents of children with chronic conditions. These findings potentially influence the lower scores observed in questions probing individualistic responsibilities. Within our study, neither disease groups nor genders demonstrated discernible differences in scale scores. Moreover, the usage of biological DMARDs, reported by 40% of patients, did not influence scale scores.

It appears that pivotal factors in gearing up for transition include lifestyle, personality traits, upbringing methods, parental attitudes, and cultural variables, transcending the severity of the disease. European Alliance of Associations for Rheumatology (EULAR)/Paediatric Rheumatology European Society (PReS) guidelines encourage family involvement in the transition process alongside physicians and patients.¹² These scales might aid in determining the extent of family engagement in crafting patient-specific transition plans.

Upon comparing age brackets across both scales, it was observed that late adolescents garnered higher transition readiness scores. This demographic exhibits enhanced cognitive functions compared to their younger counterparts, with a marked progression in independent decision-making capabilities during late adolescence.²⁰ This substantial discrepancy in scores is congruent with child development literature.

In terms of internal consistency, both scales presented acceptable Cronbach's alpha scores. Specifically, the TRANSITION-Q scale exhibited a noteworthy alpha score of 0.79, underscoring one of its strengths. Another merit of this scale is its concise duration and straightforward, comprehensible queries, making it a more favorable choice compared to the STARx scale.

Globally, several transition scales have undergone validation. In our region, the TRAQ scale was validated.²¹ This study pioneers the validation of STARx and TRANSITION-Q scales

in our country, introducing two additional viable scales besides TRAQ. We posit that these scales could facilitate the formulation of policies concerning transition preparation, an area garnering escalating importance globally.

However, this study embodies some limitations, primarily stemming from its single-center framework. Despite our clinic serving as a referral center in Turkey's most populous city, accommodating patients nationwide, the singular center aspect might not encapsulate the entire spectrum of Turkish adolescent patients. Furthermore, the study did not encompass an evaluation of the educational background and socioeconomic status of the patients and their families within the scales. Lastly, in the Turkish healthcare context, children below 18 enjoy complimentary healthcare and insurance coverage, absolving them of any financial obligations. However, after the age of 18, individuals who discontinue their education or remain unemployed lose these benefits, a factor not assessed in the utilized scales.

In conclusion, the findings postulate that the TRANSITION-Q and STARx scales could act as pivotal tools in orchestrating personalized transition plans for patients, thereby identifying their pretransition requisites.

Ethics Committee Approval: The study protocol was approved by the Ümraniye Training and Research Hospital Clinical Research Ethics Committee (date: 28.10.2021, no: B.10.1.TKH.4.34.H.GP.0.01/299). The study was conducted in accordance with the principles of the Declaration of Helsinki.

Patient Consent for Publication: A written informed consent was obtained from the patients and the parents and/or legal guardians of the patients.

Data Sharing Statement: The data that support the findings of this study are available from the corresponding author upon reasonable request.

Author Contributions: Conceptualized and designed the study, drafted the initial manuscript, and had full access to all the data in the study: R.E.Y., B.S.; All authors conducted the data analyses, drafted the initial manuscript, and had full access to all the data in the study. All authors reviewed and revised the manuscript and approved the final version of the manuscript.

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