Assessment of Transition Readiness in Adolescents with Rheumatic Diseases: A Cross-Sectional Study

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Abstract

Background: Most childhood-onset rheumatic diseases are chronic health conditions, which need long-term care throughout adulthood. A well-organized transition care is challenging and patient assessment of transition skills is needed for transfer preparation to adult care setting. The Transition Readiness Assessment Questionnaire (TRAQ) is used to assess transition skills in chronically ill patients. Currently, limited transition skill assessment data exist in pediatric patients with rheumatic diseases, especially in Asian countries. This study aimed to determine the transition readiness skills in patients with rheumatic diseases and ascertain predictive factors contributing to low transition readiness skills.

Methods: This is a cross-sectional study. All patients with rheumatic diseases aged 15-24 years were recruited. The TRAQ was cross-culturally adapted into the Thai language with good internal consistency and reliability. Patients completed the Thai TRAQ at the recent clinic visit and took the re-test at a 2-week interval. Demographic data, baseline characteristics, clinical manifestations, and disease status were collected. Descriptive and logistic regression analyses were performed.

Results: A total of 123 patients with a mean age of 17.8 ± 2.2 years were included. Median (IQR) disease duration was 6.76 (6.05) years. The most common rheumatic disease was juvenile idiopathic arthritis (47.15%), followed by systemic lupus erythematosus (36.59%). The mean TRAQ score was 3.90 ± 0.68. Studying for a bachelor's degree (odds ratio [OR] 4.64, 95% confidence interval [CI] 1.68–12.80) and independent clinic visits (OR 4.07, 95% CI 1.35–12.22) were predictors of a higher TRAQ score. Lack of knowledge on health insurance coverage and financial management were two issues causing lower TRAQ scores. Furthermore, patients with inactive disease status (OR 5.60, 95% CI 1.20–26.14) and patients, who had dependent clinic visits (OR 4.13, 95% CI 1.60–10.67), had more opportunities of getting lower TRAQ scores.

Conclusions: Patients with a higher level of education had a higher chance of successfully transitioning to adult care, whereas patients, who had inactive disease and dependent clinic visits, had less transition readiness skills. Physicians and parents should educate their children on independent living skills and paying particular attention to two issues: health insurance coverage and financial management.

Background

Most patients with childhood-onset rheumatic disease have active disease and long-term morbidity throughout adulthood [1–7]. Failure to transfer patients into an adult care setting can lead to poor outcomes and increase morbidity and mortality; therefore, preparation for the healthcare transition process during the transfer period is vitally important [8–10]. "Transition of care" is defined as the purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems [11]. Healthcare transition should maximize individual lifelong functioning by providing high-quality and developmentally appropriate healthcare services from adolescence to adulthood [12]. The transition process should be initiated at the
age of 12 years, and transfer should occur between the ages of 18 and 21 years by implementing the Six Core Elements of healthcare transition, including the assessment of transition readiness [13, 14].

There are several available transition readiness assessment tools, including the Transition Readiness Assessment Questionnaire (TRAQ) [15, 16], the TRxANSITION Scale [17], the STARx Questionnaire [18], the Am I ON TRAC for Adult Care questionnaire [19], TRANSITION-Q [20], and the Adolescent Assessment of Preparation for Transition (i.e., ADAPT) [21]. The TRAQ is a validated tool for a transition readiness assessment of self-management and self-advocacy, which are consistent with developmental skill acquisition during the transition period. The TRAQ guides healthcare providers on how to intervene and support skill acquisition [15, 22]. A systematic review of transition readiness assessment tools showed that the TRAQ has content validity, construct validity, and internal reliability [23]. A Cochrane Review in 2016 highlighted a few studies that used the TRAQ to assess transition readiness, but there was insufficient evidence certainty [24].

The American College of Rheumatology recommended that healthcare providers develop a transition of care protocol and support tools for patients with rheumatic disease, including the TRAQ, to assess transition readiness. Multicenter cohort studies of pediatric patients with rheumatic disease during the transfer period showed that 60–80% of patients had active disease and 70–85% continued taking their medications. Furthermore, disease activity increased in 30% of patients, and 30% of patients missed their first adult rheumatology visit in the post-transfer period [9, 25]. Even though the TRAQ score did not significantly predict the time to transit to an adult care setting, a higher score showed a trend towards a shorter transition period compared with a lower score. Moreover, TRAQ may be used to promote a successful transition of care [26].

The TRAQ can help physicians to evaluate adolescents' transition readiness before moving on to adult care systems. It can also enlighten healthcare professionals about unaccomplished skills that need to be facilitated before the transition. Because there is no standard transition assessment tool and no transition preparation process for patients with rheumatic disease in Thailand, this study conducted cross-culturally adapt the TRAQ into the Thai language. We aimed to determine the transition readiness skills in patients with childhood-onset rheumatic diseases and the predictive factors contributing to less transition readiness skills for better continuity of care in these patients.

**Methods**

The study adopted a cross-sectional design. Patients aged 15–21 years followed up at the Pediatric Rheumatology and Rheumatology Transition Clinics, Faculty of Medicine, Ramathibodi Hospital, Bangkok, Thailand, between 2008 and 2018 were included in the study. Patients were diagnosed with the following diseases: juvenile idiopathic arthritis (JIA), systemic lupus erythematosus (SLE), juvenile dermatomyositis (JDM), systemic sclerosis (SSc), overlap syndrome, mixed connective tissue disease, and primary systemic vasculitis, according to the International League Associations for Rheumatology classification of JIA [27], the Systemic Lupus International Collaborating Clinics classification criteria for
SLE [28], Bohan and Peter diagnostic criteria for a definite diagnosis of JDM [29, 30], the Pediatric Rheumatology European Society/American College of Rheumatology/European League against Rheumatism provisional classification criteria for juvenile SSc [31], the classification and diagnostic criteria for mixed connective tissue disease [32], and the 2012 Revised International Chapel Hill Consensus Conference Nomenclature of Vasculitides [33], respectively. Overlap syndrome is defined as the presence of two or more distinctive features of rheumatic disease.

**TRAQ assessment tool**

TRAQ version 5.0 is a validated transition readiness assessment tool with 20 self-administered questions in five domains regarding self-management and self-advocacy skills, including 1) managing medications, 2) appointment keeping, 3) tracking health issues, 4) talking with providers, and 5) managing daily activities. The question responses are scored on a scale of 1–5 as follows: 1) "no, I do not know how," 2) "no, but I want to learn," 3) "no, but I am learning to do this," 4) "yes, I have started doing this," and 5) "yes, I always do this when I need to." These options were based on the stage of change of the transtheoretical model [22], including pre-contemplation, contemplation, preparation, action, and maintenance, which are consistent with the process of skills acquisition. Overall TRAQ scores are calculated using the average scores of 20 questions, and the TRAQ scores of each domain are calculated using the average scores of the questions in each domain. The overall TRAQ scores range from 1 to 5, which represent the stage of change.

**Development of the Thai TRAQ**

At the beginning of the translation process, the author of the original questionnaire was contacted via email and granted permission for cross-cultural adaptation of the TRAQ to the Thai language. Translation was conducted according to international guidelines. Three independent translators performed the initial forward translation to the Thai language, and the forward translation was summarized in a meeting among expert pediatric rheumatologists and translators. Three independent translators performed backward translation to the English language. All versions of the translation were reviewed, and cross-cultural adaptation was performed according to the healthcare system's context. The expert committee summarized the pre-final version of the translated questionnaire with semantic and conceptual equivalence. Comprehensibility of the pre-final version was tested in a pilot sample of 10 patients with chronic rheumatic diseases. Questions with less than 80% agreement of comprehensibility were revised, and the final version was reviewed and approved by the expert committee.

**Data collection**

All patients completed the Thai TRAQ at the recent clinic visit and the re-test was performed at a 2-week interval. Demographic data and clinical characteristics, including diagnosis, disease duration, disease
activity, medications, education level, health insurance, family status, and socioeconomic status, were collected from medical records. Inactive disease status was defined according to disease-specific criteria, including Wallace's criteria for JIA [34], the SLE disease activity index [35, 36], Pediatric Rheumatology International Trials Organization criteria for JDM [37], and the Pediatric Vasculitis Activity Score (PVAS) for primary systemic vasculitis [38, 39].

**Statistical analysis**

Performance of the Thai TRAQ was validated by assessment of internal consistency using Cronbach's alpha coefficient and test–re-test reliability using the intraclass correlation coefficient (ICC). Cronbach's alpha values <0.5 were considered unacceptable, values between 0.5 and 0.59 were considered poor, values between 0.6 and 0.69 were considered questionable, values between 0.7 and 0.79 were considered acceptable, values between 0.8 and 0.89 were considered good, and values between 0.9 and 1.0 were considered excellent. ICC values <0.4 indicated poor reliability, values between 0.4 and 0.59 indicated fair reliability, values between 0.6 and 0.74 indicated good reliability, and values between 0.75 and 1.0 indicated excellent reliability. Categorical data were presented as frequencies and percentages. Continuous data were presented as means and standard deviations or medians and interquartile ranges, as appropriate. The Student's t-test or one-way analysis of variance were used for comparisons between groups. Logistic regression analysis was performed to analyze predictors of high and low TRAQ scores. Statistical significance was defined as a P-value of <0.05. Stata version 15 (Stata Corp., 2017) was used for statistical analysis.

**Results**

**Demographic data and clinical characteristics**

A total of 123 patients participated in the study (111 from the pediatric rheumatology clinic and 12 from the rheumatology transition clinic). The majority of patients were female and the most common diagnosis was JIA, followed by SLE (Table 1). Most patients in this study remained in an active disease state (78.05%) and continued taking at least one medication (92.68%), including steroid (36.59%), disease-modifying anti-rheumatic drugs (DMARDs) (81.30%), or biologic therapy (12.20%). Around 70% of patients were studying in high school, whereas the remainder studied for a bachelor's degree. Regarding health insurance, half of the patients were enrolled on the Universal Coverage Scheme (UCS), 20% were enrolled on the Civil Servant Medical Benefit Scheme (CSMBS), around 20% had no health insurance, and the remaining patients had private or company health insurance, or were receiving disability benefits.

Only some patients independently attended the clinic without a caretaker (21.95%). Among patients from the pediatric rheumatology clinic, 16.22% had a prior discussion about transition processes and policies, and 25.23% were worried about the transition to an adult setting.
Table 1
Demographic data of children with rheumatic diseases

| Variables                              | Number (%)          |
|----------------------------------------|---------------------|
| Age (years)*                           | 17.81 ± 2.19        |
| Female                                 | 89 (72.36)          |
| Disease duration (years)**             | 6.76 (6.05)         |
| Level of education                     |                     |
| Elementary school                      | 1 (0.81)            |
| High school                            | 90 (73.17)          |
| Bachelor’s degree                      | 32 (26.02)          |
| Type of health insurance               |                     |
| Universal Coverage Scheme              | 63 (51.22)          |
| Civil Servant Medical Benefit Scheme   | 24 (20.33)          |
| Company health insurance               | 3 (2.44)            |
| Private health insurance               | 3 (2.44)            |
| Disability benefit                     | 5 (4.07)            |
| None                                   | 24 (19.51)          |
| Family status                          |                     |
| Living with both parents               | 96 (78.05)          |
| Living with other relatives in the same household | 44 (35.77) |
| Diagnosis                              |                     |
| Juvenile idiopathic arthritis          | 58 (47.15)          |
| Systemic lupus erythematosus           | 45 (36.59)          |
| Scleroderma                            | 2 (1.63)            |
| Juvenile dermatomyositis               | 4 (3.25)            |
| Overlap syndrome                       | 5 (4.07)            |
| Mixed connective tissue disease        | 2 (1.63)            |
| Systemic vasculitis                    | 7 (5.69)            |

*Data are presented as mean ± standard deviation, ** median (interquartile range)
Performance Of The Thai TRAQ

Two questions in the "managing medications" and "appointment keeping" domains were adapted according to real practice and the Thai healthcare system. Question number 1 ("Do you fill the prescription if you need to?") was adapted to "Can you take a drug prescription to get the medications if you need to?" Question number 9 ("Do you apply for health insurance if you lose your current coverage?") was adapted to "Can you get the Universal Coverage Scheme or find other health care programs if your current health care program ends?" The pre-final version’s comprehensibility in the pilot sample was at least 80% agreement for all questions, and the final version was reviewed and approved by the expert committee with 100% agreement. All patients completed the TRAQ at the enrollment visit, and 117 patients completed the TRAQ re-test at a 2-week interval. Two rheumatologists assessed content validity with 100% agreement, whereas criteria validity could not be tested because of the unavailable standard readiness assessment tool. The Thai TRAQ showed excellent internal consistency (Cronbach’s alpha = 0.90) and a good-to-excellent reliability (ICC = 0.61–0.89; Table 2). The translation and cross-cultural adaptation of TRAQ from the original version to the Thai version was shown in Table 3.
Table 2
Overall TRAQ scores and TRAQ scores in each domain

| Question                           | TRAQ scores (n = 123) | Cronbach’s alpha coefficient (n = 123) | Intraclass correlation coefficient (n = 117) |
|------------------------------------|-----------------------|----------------------------------------|---------------------------------------------|
| Managing medications               | 4.30 ± 0.72           | 0.90                                   | 0.75 (0.65–0.83)                            |
| Question 1                         | 4.46 ± 0.89           | 0.90                                   | 0.75 (0.65–0.83)                            |
| Question 2                         | 4.02 ± 0.63           | 0.90                                   | 0.83 (0.76–0.89)                            |
| Question 3                         | 4.76 ± 0.63           | 0.90                                   | 0.81 (0.72–0.87)                            |
| Question 4                         | 3.96 ± 1.10           | 0.90                                   | 0.74 (0.63–0.82)                            |
| Appointment keeping                | 3.51 ± 1.00           | 0.89                                   | 0.81 (0.72–0.87)                            |
| Question 5                         | 3.52 ± 1.33           | 0.89                                   | 0.76 (0.65–0.83)                            |
| Question 6                         | 4.08 ± 1.24           | 0.90                                   | 0.80 (0.71–0.86)                            |
| Question 7                         | 4.16 ± 1.15           | 0.90                                   | 0.76 (0.65–0.83)                            |
| Question 8                         | 3.56 ± 1.39           | 0.89                                   | 0.76 (0.65–0.83)                            |
| Question 9                         | 3.21 ± 1.44           | 0.89                                   | 0.76 (0.65–0.83)                            |
| Question 10                        | 2.93 ± 1.26           | 0.89                                   | 0.69 (0.56–0.79)                            |
| Question 11                        | 3.12 ± 1.50           | 0.90                                   | 0.81 (0.73–0.87)                            |
| Tracking health issues             | 3.49 ± 0.79           | 0.89                                   | 0.86 (0.80–0.91)                            |
| Question 12                        | 4.20 ± 1.12           | 0.89                                   | 0.73 (0.61–0.81)                            |
| Question 13                        | 3.78 ± 1.20           | 0.90                                   | 0.76 (0.66–0.83)                            |
| Question 14                        | 3.48 ± 1.22           | 0.90                                   | 0.77 (0.67–0.84)                            |
| Question 15                        | 2.48 ± 1.50           | 0.91                                   | 0.82 (0.74–0.88)                            |
| Talking with providers             | 4.61 ± 0.65           | 0.90                                   | 0.68 (0.54–0.78)                            |
| Question 16                        | 4.52 ± 0.86           | 0.90                                   | 0.78 (0.68–0.85)                            |
| Question 17                        | 4.69 ± 0.67           | 0.90                                   | 0.82 (0.74–0.88)                            |
| Managing daily activities          | 4.34 ± 0.75           | 0.90                                   | 0.84 (0.77–0.89)                            |
| Question 18                        | 3.95 ± 1.17           | 0.90                                   | 0.89 (0.85–0.93)                            |
| Question 19                        | 4.42 ± 0.84           | 0.90                                   | 0.89 (0.85–0.93)                            |

*Intraclass correlation coefficient (n = 117)
| Question | TRAQ scores (n = 123) | Cronbach’s alpha coefficient (n = 123) | Intraclass correlation coefficient (n = 117) |
|----------|------------------------|----------------------------------------|--------------------------------------------|
| Question 20 | 4.64 ± 0.70            | 0.90                                   | 0.70 (0.57–0.79)                           |

*Intraclass correlation coefficient (n = 117)
Table 3
Translation and cross-cultural adaptation of Transition Readiness Assessment Questionnaire (TRAQ) from the original version to the Thai version

| Original version | Thai version |
|------------------|--------------|
| Managing Medications | Managing the medicine |
| 1. Do you fill a prescription if you need to? | 1. Can you take a drug prescription to get the medications if you need to? |
| 2. Do you know what to do if you are having a bad reaction to your medications? | 2. Do you know what you should do if there are abnormal symptoms from using the medicine? |
| 3. Do you take medications correctly and on your own? | 3. Can you take medicine correctly by yourself? |
| 4. Do you reorder medications before they run out? | 4. When the medicine runs out, can you ask for more medicine from the doctor by yourself? |
| Appointment Keeping | Managing the appointment with the doctor |
| 5. Do you call the doctor’s office to make an appointment? | 5. Can you call the hospital to make an appointment with the doctor? |
| 6. Do you follow-up on any referrals for tests, check-ups or labs? | 6. Can you go for a check-up or a blood test at a hospital near your house if the doctor asks you to do it? |
| 7. Do you arrange for your ride to medical appointments? | 7. Can you manage the travel to meet the doctor as appointed? |
| 8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)? | 8. Do you make a phone call to consult with the doctor when there are abnormal symptoms with your health, for example, drug allergies? |
| 9. Do you apply for health insurance if you lose your current coverage? | 9. Can you get the Universal Coverage Scheme or find other health care programs if your current health care program ends? |
| 10. Do you know what your health insurance covers? | 10. Do you know what your health care rights cover? |
| 11. Do you manage your money & budget household expenses (For example: use checking/debit card)? | 11. Do you manage your finance and expenditure by yourself (for example, using a debit or credit card) |
| Tracking Health Issues | Health follow-up |
| 12. Do you fill out the medical history form, including a list of your allergies? | 12. Have you written down information regarding your health, including information regarding what you are allergic to? |
| 13. Do you keep a calendar or list of medical and other appointments? | 13. Have you written down in your calendar or note the information regarding the use of the medicine and appointments to see the doctor? |
| Original version                                                                 | Thai version                                                                 |
|---------------------------------------------------------------------------------|-------------------------------------------------------------------------------|
| 14. Do you make a list of questions before the doctor’s visit?                   | 14. Do you prepare questions before going to see the doctor?                   |
| 15. Do you get financial help with school or work?                               | 15. Do you receive financial support for education or work?                    |
| Talking with Providers                                                           | Conversation with medical staff                                                |
| 16. Do you tell the doctor or nurse what you are feeling?                        | 16. Have you told the doctor or nurse how you feel or what symptoms you have? |
| 17. Do you answer questions that are asked by the doctor, nurse, or clinic staff? | 17. Can you answer questions asked by the doctor, the nurse, or hospital staff?|
| Managing Daily Activities                                                        | Managing daily activities                                                      |
| 18. Do you help plan or prepare meals/food?                                     | 18. Do you help in planning for cooking or meal preparation?                   |
| 19. Do you keep home/room clean or clean-up after meals?                         | 19. Do you clean the house/room or clean up the table after meals?            |
| 20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)? | 20. Can you go to buy something, or use the service of shops nearby to your house by yourself? |

**Traq Scores In Each Domain**

The mean TRAQ score in this study was $3.90 \pm 0.68$. Questions related to health insurance coverage (question 10) and financial support (question 15) had TRAQ scores of < 3.0. These questions scored the lowest out of all the questions, followed by question 11, which related to financial management (Table 2). The mean TRAQ scores of appointment keeping and tracking health issues were < 4.0 and significantly lower than other domains ($P < 0.01$). Comparisons of mean TRAQ scores in various parameters, including age, sex, educational level, family status, disease status, medications, and transition variables, are shown in Table 4. Patients tended to have higher TRAQ scores if they aged $\geq 18$ years and were studying for a bachelor's degree. Patients who had previously discussed the transition with the physicians and could independently visit the clinic by themselves also had higher TRAQ scores.
Table 4
Compared to TRAQ scores in various parameters (n = 123)

| Parameters                        | Total (n = 123) | TRAQ score (mean ± SD) | P-value* |
|----------------------------------|-----------------|------------------------|----------|
| Age                              |                 |                        |          |
| <18 years                        | 80              | 3.75 ± 0.71            | < 0.01   |
| ≥18 years                        | 43              | 4.26 ± 0.42            |          |
| Sex                              |                 |                        | 0.51     |
| Male                             | 34              | 3.96 ± 0.81            |          |
| Female                           | 89              | 3.87 ± 0.63            |          |
| Education level                  |                 |                        | < 0.01   |
| Below bachelor's degree          | 91              | 3.76 ± 0.71            |          |
| Attending bachelor's degree      | 32              | 4.30 ± 0.35            |          |
| Family status                    |                 |                        | 0.35     |
| Living with both parents         | 96              | 3.86 ± 0.64            |          |
| Living with one parent           | 21              | 4.00 ± 0.88            |          |
| Not living with parents          | 6               | 4.20 ± 0.50            |          |
| Disease status                   |                 |                        | 0.68     |
| Active                           | 96              | 3.91 ± 0.70            |          |
| Inactive                         | 27              | 3.85 ± 0.62            |          |
| Medication                       |                 |                        | 0.24     |
| At least one medication          | 114             | 3.92 ± 0.67            |          |
| Free of medication               | 9               | 3.64 ± 0.76            |          |
| Diagnosis                        |                 |                        | 0.24     |
| Connective tissue diseases       | 58              | 3.93 ± 0.57            |          |
| Juvenile idiopathic arthritis    | 58              | 3.83 ± 0.80            |          |
| Primary vasculitis               | 7               | 4.27 ± 0.34            |          |
| Transition discussion            | (n = 111)       |                        | 0.04     |
| Yes                              | 18              | 4.15 ± 0.56            |          |

*P < 0.05 indicates statistical significance.
### Parameters

| Parameters                   | Total (n = 123) | TRAQ score (mean ± SD) | P-value* |
|------------------------------|-----------------|------------------------|----------|
| No                           | 93              | 3.80 ± 0.69            |          |
| Transition anxiety (n = 111) |                 |                        | 0.90     |
| Yes                          | 28              | 3.84 ± 0.81            |          |
| No                           | 83              | 3.86 ± 0.64            |          |
| Independent visit            |                 |                        | < 0.01   |
| Yes                          | 27              | 4.32 ± 0.53            |          |
| No                           | 96              | 3.78 ± 0.67            |          |

*P < 0.05 indicates statistical significance.

### Predictors Of Higher And Lower Traq Scores

A mean TRAQ score of ≥ 4.0 was compatible with the action stage in the stage of change model, which means that patients had already started acquiring transition skills. Patients were classified into two groups: 1) patients with higher TRAQ scores of ≥ 4.0 or 2) patients with lower TRAQ scores of < 4.0. Predictors of higher TRAQ scores included studying for a bachelor's degree (odds ratio [OR] 4.64, 95% confidence interval [CI] 1.68–12.80) and independently attending clinic visits (OR 4.07, 95% CI 1.35–12.22), as shown in Table 5. Furthermore, this study analyzed predictors of lower TRAQ scores in two domains: 1) appointment keeping and 2) tracking health issues. Both domains had mean TRAQ scores of < 4.0. Predictors of lower TRAQ scores in these two domains were inactive disease status (OR 5.60, 95% CI 1.20–26.14) and dependent clinic visits (OR 4.13, 95% CI 1.60–10.67).
### Table 5
Predictors of a high TRAQ score.*

| Factors                        | Univariate analysis | Multivariate analysis |
|--------------------------------|---------------------|-----------------------|
|                                | Odds ratio  | 95% CI     | P-value | Odds ratio  | 95% CI     | P-value |
| Age ≥ 18 years                 | 5.22      | 2.12–12.01 | < 0.01  |            |            |         |
| Female                         | 0.68      | 0.31–1.52  | 0.35    |            |            |         |
| Studying for a bachelor's degree | 6.04      | 2.27–16.11 | < 0.01  | 4.64      | 1.68–12.80 | < 0.01 |
| Disease duration               | 1.10      | 0.99–1.20  | 0.05    |            |            |         |
| Inactive disease status        | 0.99      | 0.42–2.33  | 0.98    |            |            |         |
| Transition discussion          | 4.43      | 1.35–14.51 | 0.01    |            |            |         |
| Transition anxiety             | 1.83      | 0.76–4.38  | 0.18    |            |            |         |
| Independent visit              | 5.66      | 1.98–16.19 | < 0.01  | 4.07      | 1.35–12.22 | 0.01   |

*High TRAQ score cut off ≥ 4

### Discussion

This study developed a valid and reliable transition readiness assessment tool for Thai adolescents with rheumatic disease and identified predictors for higher and lower TRAQ scores. This study may help pediatric rheumatologists and other healthcare providers assess transition readiness skills and have better transition plans for adolescents with rheumatic diseases in the future. The results demonstrated that these patients' weaknesses were health insurance coverage and financial management in the appointment keeping and tracking health issues domains. Predictors of high transition readiness were studying for a bachelor's degree and attending independent clinic visits, whereas predictors of low transition readiness were inactive disease status and dependent clinic visits.

Some questions were adapted to ensure compatibility with our healthcare system (e.g., question number 1, which is related to the prescription filling process). The process of receiving medications in Thailand is different from Western countries. In the Thai healthcare system, patients receive medications at the hospital after leaving the doctor's office. Hospital pharmacies are the only places permitted to dispense specific drugs, especially immunosuppressive medications and biologic agents. Patients cannot get these medications from outside pharmacies. Therefore, question number 1 was adapted to assess the process of obtaining medications from pharmacists at the hospital. It might be more comfortable for
patients to obtain medicines in Thailand than in Western countries, but this is the first step toward patient independence and taking responsibility for their health.

Another question that was adapted was question number 9, which is related to health insurance. The majority of Thai citizens can apply for the UCS from the government at no cost, so they usually do not apply for other health insurance programs. The UCS covers most basic and immunosuppressive drugs used to treat rheumatic disease, except biologic agents. However, the UCS has a short expiration date, and the majority of patients need to reapply before attending their next clinic visits.

Patients whose parents work for the government or state enterprise are eligible for the CSMBS until they are 20 years old. This benefit covers all immunosuppressive medications and some biologic agents. After 20 years of age, these patients need to apply for other healthcare benefits, including the UCS or other health insurance programs. Therefore, question number 9 was adapted to “Can you get the UCS or find other health care programs, if your current health care program ends?”

The results of this study show that the percentage of patients with an active disease status (78%) was similar to previous studies (60–80%), but the percentage of patients that took at least one medication (93%) was higher compared with previous studies (70–85%)[9, 25]. Because most patients in our study had JIA or SLE, they needed long-term treatment until adulthood. Thailand has only a small number of pediatric rheumatologists; thus, a delay in patient referral to pediatric rheumatologists is expected, resulting in poor outcomes and the need for long-term medications. Additionally, our patients could not access biologic therapy as soon as indicated, which is different from developed countries’ situation. Thus, these patients still need DMARDs for long-term disease control.

Regarding the association between TRAQ score and specific diseases, previous studies have demonstrated that patients with mental illness or developmental disabilities tended to have lower TRAQ scores than patients with chronic diseases of physical function [15]. In the study by Sawicki et al. [15], patients were affected by physical disability and different types of rheumatic diseases but were not affected by mental illness; therefore, the TRAQ scores associated with each rheumatic disease were similar. The hypothesis that TRAQ scores were higher in patients with rheumatic disease without co-existing mental illness compared with patients with co-existing mental illness is supported by the TRAQ scores observed in the present study and Anelli et al study [40]. Both studies demonstrated higher TRAQ scores than other studies [15, 41], which assessed patients with cognitive impairment and mental health issues.

The skills related to health insurance coverage and financial management had the lowest TRAQ scores. Because most of the patients in this study were of a low socioeconomic status, most of them applied for the UCS.

Patients’ parents/caregivers reapplied on their behalf, although these patients were young adults.
Differences exist between Thai culture and Western culture in terms of living status and financial management. Most Thai children live with their parents, even as young adults, and they only leave their parents once they are married. Furthermore, most of them do not have a part-time job and do not undertake extra work while attending university. Therefore, health insurance and healthcare financing are managed by parents or caregivers. The results of this study emphasize that health insurance and financial management are necessary to facilitate the transition to an adult setting. Because only 16% of patients had a prior discussion about transition processes and policies, discussing these issues as part of transition sessions is essential.

With regard to good transition readiness, studying for a bachelor's degree and independent clinic visits were predictors of high TRAQ scores in this study. These findings are different from previous studies [15, 16, 41], which showed that older age is a predictor of high TRAQ scores. As mentioned previously, parents in Thai culture always take care of their children, even as young adults. Therefore, adolescents do not necessarily have independent living skills. Instead, higher education helps adolescents learn how to become independent and manage their medications. Furthermore, our study population mainly studied at the high school level. At this age, patients have not acquired sufficient living skills; thus, they might not be able to manage their lives and finances independently.

Focusing on the lower mean scores in the domains of appointment keeping and tracking health issues, we found that inactive disease status and dependent visits were predictors of lower TRAQ scores.

It is understandable that patients with inactive disease always ignore their health status and pay no attention to taking medications and seeking medical care, resulting in failure to transition to an adult care setting. Furthermore, the anxiety of Thai parents is another factor that affects children's dependency. Parents always attend the clinic with their children instead of teaching their children independence. Thus, practitioners should prepare and discuss these issues with patients during transition sessions.

To the best of our knowledge, this is the first study carried out in Thailand using the cross-cultural adapted TRAQ to assess transition readiness in adolescents with rheumatic diseases. However, this study had some limitations. First, this study was performed at a single center; thus, it might not represent the whole Thai adolescent population. Nevertheless, our hospital is the main referral center in Thailand, which receives patients from all over the country. Second, several factors associated with transition readiness, including psychological factors, strong relationships with pediatricians, and parenting style, were not assessed. Therefore, further multicenter studies with prospective cohort designs, including psychological factor assessments, are recommended.

In summary, the Thai TRAQ is a valid and reliable tool with good performance to assess transition readiness in Thai adolescents with rheumatic diseases. Patients studied for a bachelor's degree and who independently attended clinic visits have a higher chance of successful transition to adult care.
Practitioners should facilitate patient transfer from pediatric to adult care settings by preparing patients for this transition and paying particular attention to two issues: health insurance coverage and financial management. Moreover, it is important to raise awareness of the disease to the patients especially during inactive disease. Parents should teach their children independent living skills. Well-planned transitional care may help adolescents to achieve a successful transition and achieve good health and wellbeing.

**Declarations**

**Ethics approval and consent to participate**

Written informed consent was obtained from patients and their parents prior to enrollment. The study was approved by the Research and Ethics Committee of the Faculty of Medicine, Ramathibodi Hospital [EC number 2561/306] and was carried out in accordance with the Declaration of Helsinki.

**Availability of data and materials**

The datasets analyzed during the current study are not publicly available due to confidentiality agreement of the data with the participants but are available from the corresponding author on reasonable request.

**Competing interests**

The authors declare that they have no competing interests.

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**Authors’ contributions**

SK participated on data acquisition, analysis, and have drafted the manuscript. SV had contributions to conception and study design, data analysis, and manuscript editing. BL, SS, and PN participated on data analysis and manuscript editing. All authors read and approved the final manuscript.

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