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Exploring the Association of Sociodemographic Factors and Primary Diagnosis With Transition Readiness in Adolescents With Rheumatic Disease

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Objective. Transitioning from pediatric to adult care is challenging for adolescents with chronic health conditions. The Transition Readiness Assessment Questionnaire (TRAQ) is a validated tool for measuring transition readiness in pediatric patients with chronic diseases. This study examines the association of sociodemographic factors and primary diagnosis with transition readiness in adolescents with rheumatic disease using TRAQ scores.

Methods. We conducted a retrospective chart review of 882 adolescents with rheumatic diseases, aged 14 to 19 years, from September 2019 to December 2021. TRAQ scores, primary diagnosis, and demographic characteristics were collected. Bivariate and multiple linear regression analyses were used to identify predictors of transition readiness.

Results. We collected 882 TRAQs. Lupus diagnosis was significantly associated with higher TRAQ scores, whereas juvenile dermatomyositis diagnosis negatively influenced transition readiness. Non-Hispanic ethnicity correlated with higher scores in managing medications and tracking health issues, and male gender was significantly linked to lower scores in tracking health issues and managing daily activities. There was no association between TRAQ scores and age, race, primary language of the parent, insurance type, median household income, and suicidality screen. A total of 118 patients completed two TRAQs with a mean interval of 13.5 months. There was no significant change in TRAQ scores over time. However, Hispanic patients, patients with Spanish-speaking parents, and patients with lupus scored higher on the second TRAQ.

Conclusion. In our cohort, transition readiness varied by primary diagnosis. Transition plans tailored to the needs of vulnerable adolescents are required to enhance health management skills and facilitate a successful transition.

INTRODUCTION

Pediatric to adult health care transition is a vulnerable period for adolescents with chronic diseases.[1–3] This stage can be associated with adverse outcomes including discontinuation of care, health complications, increased preventable emergency room visits, and mortality.[3,4]

Insurance coverage and access to qualified adult specialists are among the most common barriers to health care transition in the United States of America.[4] Sociodemographic factors, like ethnicity, education level, and economic status, can also significantly impact transition outcomes in many chronic illnesses.[4] A common barrier, although less studied, is inadequate transition preparation in early adolescence leading to poor knowledge of the transition process and a lack of self-management skills.[1,3,4] Evidently, structured transition plans often result in positive population health outcomes,[5] and health literacy is associated with increased transition readiness.[6,7] The American Academy of Pediatrics (AAP) encourages providers to develop a transition of care protocol for their adolescent patients and to regularly assess their transition readiness using an objective tool.[1]

Adolescents in the Scottish Rite for Children (SRC) rheumatology clinic in Dallas, Texas, complete the Transition Readiness Assessment Questionnaire (TRAQ) annually. The TRAQ is a self-reported tool validated in pediatric patients with chronic health conditions. It is designed to measure decision-making and self-advocacy skills of adolescents. Higher TRAQ scores are associated with higher perceived confidence in managing one's

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own disease.[2] The TRAQ has good internal reliability and criterion validity[8] and is considered among the best available transition readiness screening tools.[9] However, it is not disease specific, and its predictive validity and correlation with transition outcomes remain unknown.[8,9] The objective of this study is to investigate the association of demographic factors and primary diagnosis with transition readiness in adolescents with rheumatic diseases using TRAQ scores.

PATIENTS AND METHODS

Participants. We conducted a retrospective chart review of pediatric patients, with any rheumatic condition, aged ≥14 years, and observed at the SRC rheumatology clinic. Patients were included if they completed a TRAQ between September 2019 and December 2021. If a patient completed multiple TRAQs during that period, then the most recent questionnaire was used.

Adolescents in the SRC rheumatology clinic receive a written transition policy annually, starting at age 14 years. The policy offers guidance for identifying an adult provider and managing medications, health records, and insurance changes. A short survey was used to assess the adolescents' perception of the clinic's current transition preparation efforts. The survey included two questions: "Have you ever received a copy of the rheumatology transition policy?" and "Has your care team ever talked about when you should transition to an adult rheumatology provider?" The study was exempt from institutional review board review and was approved by the clinical quality and performance improvement committee at SRC. TRAQ responses and demographic characteristics of the patients were extracted from the electronic medical records at SRC.

Outcome and independent variables. The primary outcome measure of the study was transition readiness scores of adolescents with rheumatic diseases as measured by the TRAQ. The TRAQ includes 20 questions assessing five domains of transition readiness: managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities. Each question is scored on a scale of 1 to 5 with 1 indicating "No, I do not know how" and 5 indicating "Yes, I always do this when I need to." The average score of each domain is used to calculate the overall TRAQ score. The total score is out of five, and a higher score reflects higher perceived confidence in transition skills.

Independent variables included race, ethnicity, biologic sex, primary language of the parent/caregiver (English or Spanish), insurance coverage (public insurance, commercial insurance, or no insurance), age at the time of TRAQ completion, household median income in the past 12 months, results of suicidality screen, and primary diagnosis. Median household income in the past 12 months was estimated using the zip codes of the patients and the US Census Bureau 2016 to 2020 American Community Survey (in 2020 inflation-adjusted dollars).

Statistical analysis. We conducted a descriptive statistical analysis. Bivariate analysis was performed to evaluate the association between each independent variable and transition readiness. Continuous variables were first examined for normality with the Shapiro-Wilk test; the *t*-test and Mann-Whitney test for two-group comparisons were used as appropriate. For more than two groups, we used analysis of variance and Kruskal-Wallis tests as appropriate. Spearman's correlation coefficients were used to assess the correlation between age and TRAQ scores. Paired *t*-test and paired Wilcoxon signed-rank test were used to compare scores of the first and second TRAQs. Multiple linear regression was then used to evaluate the simultaneous influence of independent variables on transition readiness identifying significant predictors while controlling for potential confounders. $P < 0.05$ was considered statistically significant. The statistical analyses were performed using SAS 9.4 and R.

RESULTS

Study population. Between September 2019 and December 2021, a total of 1,121 TRAQs were collected. Completing the TRAQ is mandatory at the SRC clinic. To eliminate duplicate responses, only the most recent questionnaire was used for patients who completed more than one TRAQ during this period. After applying this criterion, the final dataset consisted of 882 TRAQs. A total of 64% of the study cohort are established patients already receiving ongoing care at our clinic at the time of TRAQ completion. A total of 118 patients completed two TRAQs with a mean time difference of 13.5 months between the first and second questionnaire. The time difference ranged from a minimum of 11 months to a maximum of 16 months.

The age of participants ranged from 14 to 19 years with an average age of 15.7 years. Most adolescents were female (72%) and White (78%). A total of 11% of the patients were African American, 5% were Asian, 1% were American Indian/Alaska Native, and 5% were unknown. A total of 29% of the study cohort were of Hispanic ethnicity, and 90% of parents/caregivers listed English as their primary language. Most of the patients had commercial insurance (60%), 28% were government funded, and 12% were uninsured. Thirty-six patients (4%) had a positive suicidality screen. The sociodemographic characteristics of the participants are summarized in Table 1.

In our cohort, the most common disease was juvenile idiopathic arthritis (42%) followed by hypermobility/amplified musculoskeletal pain syndrome (30%); "other," which included periodic fever syndromes and auto-inflammatory diseases (11%); systemic lupus erythematosus (SLE) or cutaneous lupus erythematosus (8%); juvenile dermatomyositis (JDM; 4%); vasculitis (3%); and scleroderma (2%) (Table 2).

Table 1. Sociodemographic characteristics of the study cohort

Characteristics	Patients (N = 882)
Mean age, year (SD)	15.7 (1.3)
Gender, n (%)	
Female	635 (72)
Male	247 (28)
Race, n (%)	
White	686 (78)
African American	96 (11)
Asian American	45 (5)
American Indian/Alaska Native	9 (1)
Unknown	46 (5)
Ethnicity, n (%)	
Hispanic	256 (29)
Non-Hispanic	626 (71)
Primary language of the parent, n (%)	
English	795 (90)
Spanish	87 (10)
Type of insurance, n (%)	
No insurance	102 (12)
Private insurance	530 (60)
Public insurance	250 (28)
Median household income in the past 12 months, n (%)	
<$25,000	0 (0)
$25,000–$49,999	162 (18)
$50,000–$74,999	323 (36.5)
$75,000–$99,999	202 (23)
$100,000–$149,999	162 (18)
$150,000–$199,999	29 (3)
>$200,000	4 (0.5)

According to the electronic medical records, among our cohort of 882 patients, 373 (42%) received a copy of the transition policy in their preferred language as part of their after-visit summary paperwork. However, only (22%) answered "Yes" to "Have you ever received a copy of the rheumatology transition policy?" Furthermore, only 24% of adolescents answered "Yes" to "Has your care team ever discussed with you the age at which you should transition to an adult rheumatologist?" (Table 3). The mean ± SD TRAQ score was 3.87 ± 0.93. Our cohort scored the highest in talking with providers (average score of 4.69) and the lowest in appointment keeping (average score of 3.55).

Bivariate analysis. Non-Hispanic ethnicity was associated with a higher TRAQ score compared with Hispanic ethnicity (3.9 vs 3.79; P = 0.01) (Figure 1). Non-Hispanic adolescents also scored higher than Hispanic adolescents in managing medications (3.91 vs 3.76; P = 0.01), tracking health issues (3.66 vs 3.39; P = 0.0001), and managing daily activities (4.47 vs 4.38; P = 0.006).

Table 2. Distribution of rheumatic diseases in the study cohort*

Primary diagnosis	Patients (N = 882), n (%)
Juvenile idiopathic arthritis	366 (42)
Hypermobility/AMPS	263 (30)
Other[a]	99 (11)
Systemic or cutaneous lupus	72 (8)
Juvenile dermatomyositis	37 (4)
Vasculitis	26 (3)
Localized or systemic sclerosis	19 (2)

*AMPS, amplified musculoskeletal pain syndrome.

[a] Other includes periodic fever syndromes and auto-inflammatory disease.

Table 3. Short survey results

Question	Answer, n (%)
Have you ever received a copy of the rheumatology transition policy?	
Yes	192 (22)
No	680 (77)
Null	10 (1)
Has your care team ever talked about when you should transition to an adult rheumatology provider?	
Yes	214 (24)
No	661 (75)
Null	7 (1)

Lupus diagnosis was associated with the highest TRAQ score, whereas JDM diagnosis was associated with the lowest TRAQ score (4.08 vs 3.42; P = 0.03) (Figure 2). Patients with JDM also scored the lowest in managing medications (P = 0.01), tracking health issues (P = 0.01), and talking with providers (P = 0.03).

There was no association between the overall TRAQ score and gender, age, race, primary language of the parent, insurance type, median household income, and positive suicidality screen. Female adolescents scored higher than male adolescents in managing daily activities (4.51 vs 4.28; P = 0.003) and tracking health issues (3.64 vs 3.44; P = 0.04). Patients with English-speaking parents had higher scores than patients with Spanish-speaking parents in tracking health issues (3.62 vs 3.29; P = 0.005).

There was no significant difference between the two TRAQ scores completed 11 to 16 months apart. However, the managing medications score was higher on the second TRAQ (3.67 vs 3.85; P = 0.04). Hispanic patients scored higher on the second TRAQ (3.65 vs 3.91; P = 0.02). They also scored higher on the second TRAQ in managing medications (P = 0.004) and tracking health issues (P = 0.04). Patients with Spanish-speaking parents scored higher on the second TRAQ (3.80 vs 4.21; P = 0.008). Additionally, they scored higher on the second TRAQ in managing medications (P = 0.01) and managing daily activities (P = 0.02). Patients with lupus had higher scores on the second TRAQ (3.72 vs 4.13; P = 0.009). They also scored higher on the second TRAQ in tracking health issues (P = 0.009), talking with providers (P = 0.04), and managing daily activities (P = 0.009).

Multivariate linear regression analysis. Multiple linear regression analysis is a statistical tool used to evaluate the association between a dependent variable and two or more independent variables while controlling for possible confounding factors. We used a multiple linear regression model to explore the association of sociodemographic factors and primary diagnosis with

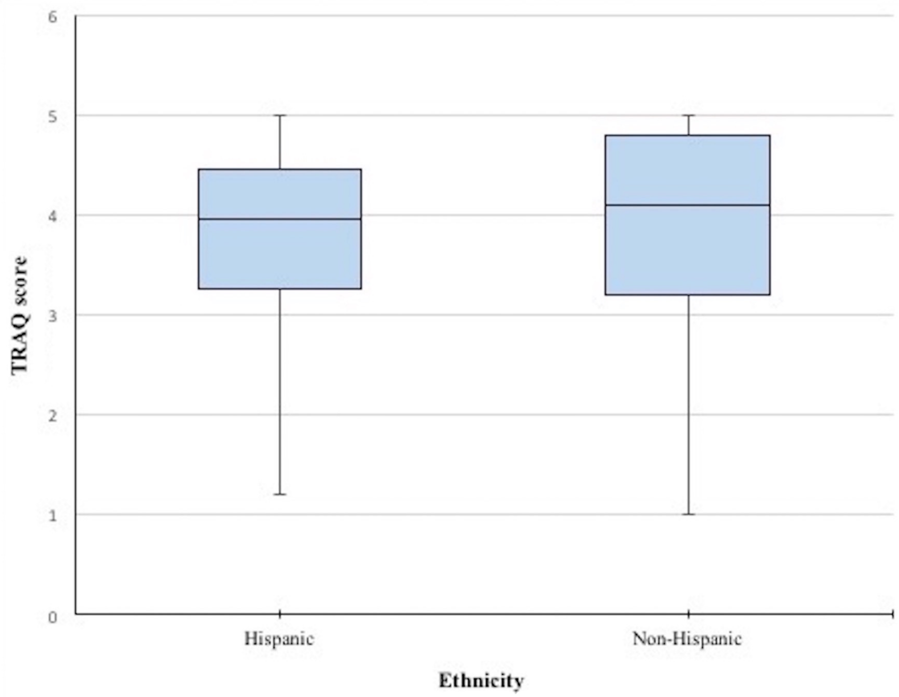

Figure 1. TRAQ scores variation by ethnicity. TRAQ, Transition Readiness Assessment Questionnaire.

transition readiness. The model was statistically significant ($P = 0.017$) with an adjusted R^2 of 0.015. Lupus diagnosis was significantly associated with higher transition readiness ($\beta = 0.28$, $P = 0.022$), whereas JDM diagnosis was negatively associated with transition readiness ($\beta = -0.39$, $P = 0.014$). Sociodemographic factors did not contribute to the overall TRAQ score.

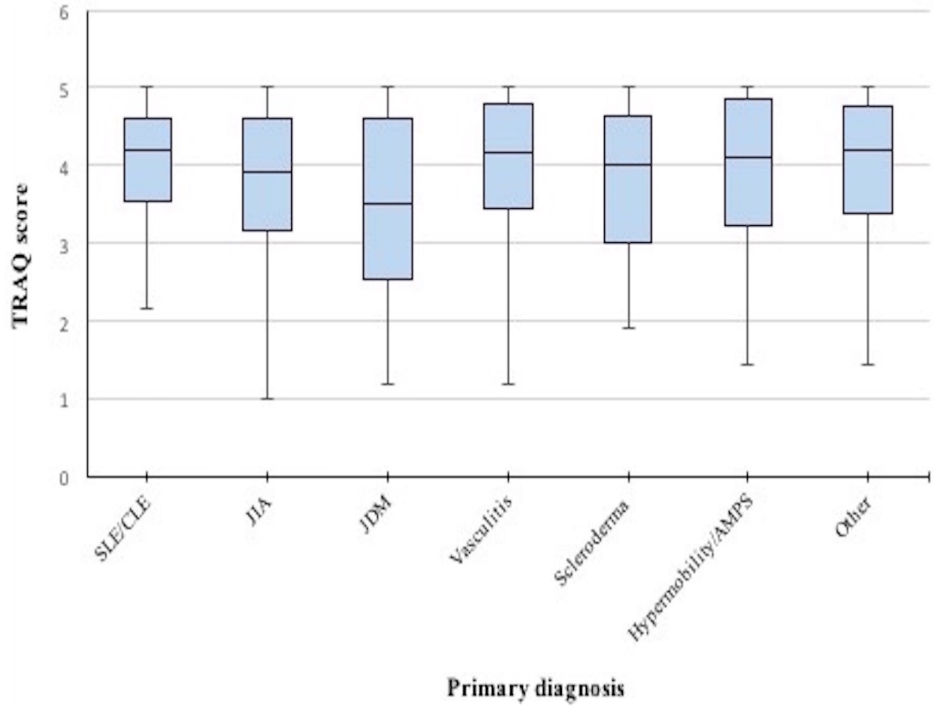

Figure 2. TRAQ scores variation by diagnosis. "Other" includes periodic fever syndromes and auto-inflammatory diseases. AMPS, amplified musculoskeletal pain syndrome; CLE, cutaneous lupus erythematosus; JDM, juvenile dermatomyositis; JIA, juvenile idiopathic arthritis; SLE, systemic lupus erythematosus; TRAQ, Transition Readiness Assessment Questionnaire.

Table 4. Multiple linear regression analyses for Transition Readiness Assessment Questionnaire domains, including significant variables*

Variables	Managing medications		Tracking health issues		Talking with providers		Managing daily activities	
	β	SE	β	SE	β	SE	β	SE
Gender (male)	−0.14	0.08	−0.21[c]	0.09	−0.09	0.05	−0.22[a]	0.06
Ethnicity (non-Hispanic)	−0.18[c]	0.09	0.26[b]	0.10	−0.05	0.05	0.09	0.06
Diagnosis (lupus)	0.45[b]	0.14	0.33[c]	0.15	0.14	0.08	0.07	0.10
Diagnosis (JDM)	−0.26	0.18	−0.45[c]	0.20	−0.42[a]	0.10	−0.26[c]	0.13

*β, Beta coefficient; JDM, juvenile dermatomyositis; SE, Standard error.

[a] $P < 0.001$.

[b] $P < 0.01$.

[c] $P < 0.05$.

Multiple linear regression models were used to assess the relationship of sociodemographic factors and primary diagnosis with each domain of the TRAQ. The models for managing medications, tracking health issues, talking with providers, and managing daily activities were statistically significant and showed the following. (1) Lupus diagnosis and non-Hispanic ethnicity were significantly associated with higher scores in managing medications. (2) Lupus diagnosis and non-Hispanic ethnicity were significantly linked to higher scores in tracking health issues whereas JDM diagnosis and male gender were significantly associated with lower scores. (3) JDM diagnosis significantly contributed toward lower scores in talking with providers and male gender showed a marginal effect ($P = 0.055$), with male adolescents scoring lower than female adolescents. (4) JDM diagnosis and male gender showed a significant association with lower scores in managing daily activities. The results are summarized in Table 4. There was no significant multicollinearity (variance inflation factor value <2 for all models).

DISCUSSION

In this study, we sought to evaluate the association of demographic factors and primary diagnosis with transition readiness in adolescents with rheumatic diseases using their TRAQ scores. In our cohort, the diagnosis of lupus was significantly associated with higher transition readiness, whereas the diagnosis of JDM negatively influenced readiness to transition. There was no significant correlation between the studied sociodemographic variables and the overall TRAQ scores. However, non-Hispanic ethnicity positively correlated with higher scores in managing medications and tracking health issues, whereas male gender was significantly linked to lower scores in tracking health issues and managing daily activities. Age was not a significant predictor of transition readiness, and there was no evident change in TRAQ scores over time.

Our study adds to the growing literature demonstrating that ethnic disparities negatively impact health care transition. A study following patients with childhood-onset SLE showed that Hispanic ethnicity was associated with a higher risk of end-stage renal disease and death after transfer to adult care.[10] Young adults from underserved populations are less likely to receive adequate transition preparation.[11] Additionally, they may have limited access to health care as they transition into adulthood owing to lack of insurance and therefore have poor adherence to care.[11] Furthermore, the language barrier can be a challenge for patients and parents from underrepresented ethnic groups. A systemic review showed that parental low English proficiency is associated with reduced access to health care for children with special health care needs.[12] Consequently, these patients and caregivers may encounter difficulties in comprehending medical information, navigating the complex health care system, and advocating for their medical needs. These barriers likely played a role in the lower managing medications and tracking health issues scores observed in Hispanic patients compared with non-Hispanic patients.

Hispanic patients and patients with Spanish-speaking parents had improved TRAQ scores 1 year later as opposed to non-Hispanic patients and patients with English-speaking parents who had unchanged scores. This suggests that Hispanic patients and patients with non–English-speaking parents are more likely to respond positively to consistent counseling and sustained support over time.

There are conflicting reports in the literature regarding the influence of disease type and severity on transition readiness. Among patients with sickle cell disease, greater disease severity was associated with better caregiver-reported transition readiness and better transition outcomes owing to increased knowledge about the condition and adherence with appointments.[13] On the other hand, disease severity and burden were not significant predictors of transition readiness in adolescents with chronic kidney disease,[14] congenital heart disease, and heart transplant.[15] The higher readiness scores seen consistently among our patients with lupus may be linked to their frequent hospital visits and interactions with multiple specialists. Patients with SLE are seen in our clinic at least every 3 months, and many of them have frequent inpatient admissions for infusions. Therefore, patients with lupus receive regular counseling emphasizing disease awareness, medications adherence, and self-advocacy skills. Furthermore, the variation in the disease course can influence transition readiness. SLE disease activity often persists into adulthood, making transition planning a priority. A significant number of patients with SLE have active disease and life-threatening complications including lupus nephritis at the time of transition.[16,17] Therefore, our team members have consistent elaborate conversations highlighting the significance of continuous health care and the need to practice managing their health independently. On the other hand, many patients with JDM have less severe or inactive disease at the time of transfer.[18,19] Thus, they may feel less motivated to prepare for the transition of care because their disease is often quiescent or stable. A study assessing transition readiness in pediatric rheumatology patients in Thailand showed that inactive disease was a predictor for low score in the tracking health issues domain of the TRAQ owing to a low concern about health.[20]

Our finding that female gender is associated with higher scores in managing daily activities and tracking health issues is consistent with previous reports. A study of Turkish adolescents with rheumatic diseases found that female patients scored higher than male patients in the self-management domains.[21] In Canada, a study of adolescents with acquired brain injury involved in transition programs showed female patients felt comfortable managing their care whereas male patients relied more on their parents.[22] The study also noted a significant difference in the extent of family involvement in the transition process between the two genders; family support and encouragement toward independence was reported more frequently by female patients.[22] In adolescents with congenital heart disease and Turner syndrome, transition readiness scores correlated positively with the parents' perception of their children's readiness, proving that encouragement from parents helps adolescents feel empowered and confident in their self-management skills.[23,24]

There are also major differences in coping strategies and behaviors between the two genders: female patients are more likely to seek support from family and friends,[18] whereas male patients tend to avoid expressing their emotions and concerns and use exercise and sports as coping tools.[25] Psychosocial support is crucial for effectively coping with a chronic disease. Evidently, parental support was associated with better treatment compliance in adolescents with type I diabetes.[26] In addition, social support was an important facilitator of transition in adolescents with HIV,[27] whereas less peer support was associated with negative feelings about the transition to adult care in adolescents with gastrointestinal, renal, and rheumatic diseases.[28]

In our cohort, there was no correlation between TRAQ scores and patient age. This finding is not consistent with the transition literature. Older patient age was associated with higher TRAQ scores in adolescents with Turner syndrome,[24] HIV,[29] and congenital heart disease.[23] TRAQ scores also increased with age in adolescents with inflammatory bowel disease, with the highest rate of increase seen in male adolescents between the ages 17 and 19 years.[30] Self-management skills, like appointment keeping, improved with older age in adolescents with type I diabetes.[31] These studies support the hypothesis that adolescents acquire more skills and knowledge with age leading to increased maturity, independence, and sense of responsibility. However, there are conflicting results about the correlation of age and transition readiness in young adults with rheumatic diseases. Lazaroff et al noted that patient activation, female sex, and older age were predictors of higher TRAQ scores in adolescents with rheumatic diseases.[32] This contradicted the study of Sönmez et al, which found no correlation between age and TRAQ scores in patients with rheumatic diseases.[21] Jensen et al also did not observe a correlation between age and transition readiness in patients with rheumatic, gastrointestinal, and endocrine diseases.[33] These conflicting results may be because of the impact of other confounders on the association between patient age and transition readiness, including cognitive function, resilience, social support, and health literacy. For this reason, the AAP recommends considering emotional maturity and developmental level, in addition to age, when determining the optimal timing of the transition to adult care.[1]

Although our records indicate that 42% of patients received the transition of care policy, only 22% of adolescents self-reported receiving it. This discrepancy raises concerns about the effectiveness of distributing handouts and highlights the need for more interactive methods to ensure adolescents not only receive the handout but also comprehend and retain its content.

For many young adults, preparing for transition is not a priority compared with the other aspects of adulthood like education and career.[1] Furthermore, many young adults tend to avoid discussing transition of care owing to anxiety, denial, and difficulty coping with the diagnosis.[34] A recent study showed that poor coping was negatively related to transition readiness in young adults.[34] The same study also showed that anxiety was a major mediator influencing the relationship between coping and transition readiness.[34] Therefore, a structured and interactive discussion is more beneficial to introduce health care transition to adolescents, provide them with guidance, and emphasize the crucial role of successful transition in their overall health and well-being. In fact, transition programs using education and skill-building activities resulted in positive transition outcomes in patients with rheumatic diseases.[35]

Our study has several limitations. First, it was performed at a single institution located in a geographic area with a specific ethnic, socioeconomic, and disease distribution. Therefore, these results may not apply to all pediatric rheumatology patients across the United States. Furthermore, only 4% of our cohort had JDM, which may have skewed the results. Second, because our data are cross-sectional, no definitive causality can be concluded between our variables and transition readiness. Third, transition readiness was assessed using self-reported data from TRAQ scores. These data reflect the adolescents' perception of their self-management skills, which may not accurately reflect their actual abilities and transition readiness.

The period between the completion of the first and second TRAQ was most likely not enough time for adolescents to build and incorporate new skills and feel more confident managing their own health. Some self-management competencies may take years to master. Furthermore, our study was conducted during the COVID-19 pandemic, thus, the long social isolation and stressors may have affected the adolescents' ability to incorporate new skills into their daily routine. Finally, the low adjusted R^2 value of the multiple linear regression analysis suggests that the included factors only explain part of the variability in transition readiness. Other factors, like health literacy, family support, and resilience, may play a more prominent role in predicting readiness to transition.

Despite these limitations, our project is one of the few studies to highlight the variations in health care transition readiness among adolescents with different rheumatic diseases. Our large racially and clinically diverse patient population helped identify factors that may predict increased vulnerability during health care transition, such as primary diagnosis, gender, and ethnicity. Additionally, our study demonstrated that the distribution of a written transition of care protocol is not an effective method to improve transition readiness. Our findings add to the growing evidence that patients have different transition preparation needs depending on their social background and disease circumstances. Therefore, interactive, family-centered conversations and interventions tailored to the specific needs of patients are imperative to enhance their health management competencies, facilitate the transition process, and improve long-term health outcomes.

In conclusion, health care transition readiness is a complex process influenced by interrelated factors like sociodemographic characteristics, disease type and severity, parental education level, health literacy, family support, cognitive function, and mental resilience.[21,36] Future research should explore the correlation between these factors and objective transition outcome measures like appointment keeping, medications compliance, and disease complications in young adults with rheumatic diseases.[21]

AUTHOR CONTRIBUTIONS

All authors contributed to at least one of the following manuscript preparation roles: conceptualization AND/OR methodology, software, investigation, formal analysis, data curation, visualization, and validation AND drafting or reviewing/editing the final draft. As corresponding author, Dr Al Manaa confirms that all authors have provided the final approval of the version to be published and takes responsibility for the affirmations regarding article submission (eg, not under consideration by another journal), the integrity of the data presented, and the statements regarding compliance with institutional review board/Declaration of Helsinki requirements.

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