

#### **Arthritis Care & Research**

Vol. 71, No. 9, September 2019, pp 1264–1269 DOI 10.1002/acr.23739 © 2018, American College of Rheumatology

# **BRIEF REPORT**

# How Do Health Literacy, Numeric Competencies, and Patient Activation Relate to Transition Readiness in Adolescents and Young Adults With Rheumatic Diseases?

Samuel M. Lazaroff,<sup>1</sup> Alexa Meara,<sup>1</sup> Mary Kate Tompkins,<sup>1</sup> Ellen Peters,<sup>1</sup> and Stacy P. Ardoin<sup>2</sup>

**Objective.** To evaluate how demographics, health literacy, numeracy, and patient activation are related to transition readiness in adolescent and young adult (AYA) patients and to describe how parent/guardian (PG) performance on these metrics predicts AYA patients' transition readiness.

**Methods.** In this single center, cross-sectional study, consecutive English-speaking AYA patients ages 17–21 years and PGs were recruited from outpatient rheumatology clinics. Participants completed the following self-reported instruments: demographic questionnaire, Short Test of Fundamental Health Literacy, Objective Numeracy Scale, Subjective Numeracy Scale, Symbolic-number mapping, Patient Activation Measure, and Transition Readiness Assessment Questionnaire (TRAQ; AYA patients only).

**Results.** Ninety-one AYA patients participated in the study, of whom 64 of 91 (70%) had juvenile idiopathic arthritis, and 54 PGs. Mean  $\pm$  SD TRAQ score was 4.0  $\pm$  0.65, correlating with "I am starting to do this" stage of change. Most participants (98%) had adequate health literacy. Multivariable regression analysis showed that AYA patients of female sex, older age, and higher patient activation significantly predicted higher TRAQ scores (P < 0.05). No PG characteristics were linked to higher AYA patient TRAQ scores.

**Conclusions.** Transition readiness in AYA patients as measured by TRAQ is associated with female sex, older age, and higher patient activation. Though sex and age are nonmodifiable, interventions to boost patient activation represent a promising opportunity to improve transition readiness and outcomes.

### **INTRODUCTION**

Since the mid-1980s, leaders in the fields of pediatrics and adolescent, internal, and family medicine have emphasized the need to study and improve the chronic condition transition process, defined as the "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems" (1). Three decades later, our knowledge on the subject remains incomplete, with insufficient quantitative data on the factors that contribute to successful transition in order to inform best practices and improve outcomes (2). Knowledge gaps in transition from pediatric to adult care include understanding the relationships among patient and parent health literacy, numeracy, patient activation, and transition

readiness. These skills are vital in provider-patient communication and health care system navigation.

Health literacy is the "capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (3). Poor health literacy is linked to medication non-adherence, poor appointment keeping, poorer health knowledge, and poorer self-management of medical conditions in several disease states (3,4). Likewise, lower numeracy, "the ability to use and understand numbers in daily life," in the medical setting is associated with higher rates of comorbidities, unrealistic expectations for treatment options, and poorer disease control (5,6). Both health literacy and numeracy are key to comprehending health care information, but a study by Hibbard and colleagues demonstrated that comprehension alone is insufficient

Supported by the Ohio State University College of Medicine Barnes Research Scholarship awarded to Mr. Lazaroff.

<sup>&</sup>lt;sup>1</sup>Samuel M. Lazaroff, BA, Alexa Meara, MD, Mary Kate Tompkins, MS, Ellen Peters, PhD: Ohio State University, Columbus; <sup>2</sup>Stacy P. Ardoin, MD, MS: Ohio State University and Nationwide Children's Hospital, Columbus.

Dr. Peters owns stock or stock options in Insignia Health, which owns the Patient Activation Measure used in this research. Dr. Ardoin has received

consulting fees from the American Board of Pediatrics, Novartis, and Aurinia Pharmaceuticals (less than \$10,000 each). No other disclosures relevant to this article were reported.

Address correspondence to Stacy P. Ardoin, MD, MS, 700 Children's Drive, Columbus, Ohio 43205. E-mail: stacy.ardoin@osumc.edu.

Submitted for publication January 4, 2018; accepted in revised form August 21, 2018.

#### SIGNIFICANCE & INNOVATIONS

- Female sex, older age, and higher patient activation scores predicted transition readiness in adolescent/young adult patients, as measured by the Transition Readiness Assessment Questionnaire.
- Parent competencies and adolescent/young adult health literacy and numeracy scores did not predict transition readiness.
- Interventions shown to increase patient activation may improve transition readiness.

for patients to make informed choices (7). Patient activation (taking an active role in managing one's own health and health care) is an additional measure of patients' abilities to weigh choices and make health care decisions. Increases in patient activation are associated with increased engagement in healthier lifestyle behaviors and fewer hospital visits (7).

However, the transition process involves not only adolescent and young adult (AYA) patients but also their parents/guardians (PGs), with control over health care decisions gradually transferred from PGs to the AYA patient. Health literacy, numeracy, patient activation, and transition readiness have been studied in adolescent patients, but relationships between AYA patients and PGs in the setting of transition remain understudied (3,4,7,8). A study by Chisolm et al demonstrated the prevalence of health literate congruent parent-child dyads (i.e., both parent and patient have adequate health literacy) and incongruent dyads within a low socioeconomic (SES) population, suggesting the need for providers to consider both the abilities of the patient as well as their PG in health care navigation. Notably, 23% of teens with sub-adequate health literacy also had a PG with poor health literacy (9), and low parental numeracy has been linked to over- and under-weight children (10).

Focusing on pediatric rheumatology, a study by Bingham et al (2) showed that older patient age, younger PG age, having a family member with a similar disease, longer disease duration, having other comorbidities, and having had a summer job correlated with increased self-reported autonomy in accessing medical care. These findings highlight important personal characteristics that may contribute to successful transition in AYA patients. The goal of this study was to evaluate the association of AYA and PG health literacy, numeracy, and patient activation with AYA transition readiness in a cohort of AYA patients with chronic rheumatic conditions.

# **MATERIALS AND METHODS**

In this single center, cross-sectional study, consecutive AYA patients and 1 PG of each AYA patient were recruited from the outpatient rheumatology clinic from May to August of 2016; AYA patient inclusion criteria included those who were ages 17–21,

English-proficient, and capable of completing the questionnaires. Participants ages ≥18 years provided verbal consent to participate; those younger than 18 provided verbal assent. The Nationwide Children's Hospital Institutional Review Board approved the protocol in regard to ethics.

**Data collection.** AYA patients completed demographic questionnaires and the instruments on paper (described below). When possible, PGs completed all measures except the Transition Readiness Assessment Questionnaire (TRAQ). PGs were instructed to assess themselves on the measures, not the AYA patient. Data collected on paper were entered into a secure database for analysis. No personal health information was collected or recorded.

**Measures.** Demographics. All participants provided demographic information including sex, race, ethnicity, marital status, insurance coverage, employment status, household income, and education. Patients also reported their rheumatologic diagnosis and month/year of diagnosis.

Health literacy. Health literacy was assessed using the Short Test of Fundamental Health Literacy (sTOFHLA), a 36-item assessment designed to measure reading comprehension (11). Continuous sTOFHLA scores were used in analyses. Scores in the range 0–16 are defined as inadequate health literacy, 17–22 as marginal, and 23–36 as adequate. This test contains 2 English passages written at 4th grade and 10th grade reading levels and has been widely validated across disease states (11).

Transition Readiness Assessment Questionnaire (TRAQ). The TRAQ (version 5.0), a 20-item survey that measures proficiency in 5 domains (including managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities), was used to measure the readiness of AYA patients to transition to adult providers. Each item is scored on a scale of 1 ("No, I do not know how") to 5 ("Yes, I always do this when I need"), based upon the stages of change model. Item scores were averaged to produce an overall score (12). The TRAQ can be used for any chronic medical condition and has been validated or studied in populations including healthy individuals and patients with cystic fibrosis, congenital heart disease, sickle cell disease, and those with rheumatologic, gastroenterologic, and endocrinous disorders (12,13-15). The TRAQ has been utilized as a key measure in interventional and transition observational studies (13-15). To date, the TRAQ is the most extensively validated disease-neutral transition readiness assessment tool.

Objective Numeracy Scale (ONS). The ONS includes 8 math questions that are focused primarily on percentages and proportions. The number of correct questions is the total score, with questions left blank scored as incorrect. Possible scores range from 0 to 8; higher scores indicate higher levels of numeric

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ability. This tool was developed to have a broader range of difficulty relative to other tests available to researchers (16).

Subjective Numeracy Scale (SNS). The SNS is an 8-question survey assessing self-perceptions of math abilities that relate positively to objective numeracy scores (17). Patients rate themselves from 1 to 6 on each of 8 items, and an average is computed. Patients with high overall scores believe they have high math capabilities and generally prefer to use numbers instead of words. Higher SNS scores have been related to greater confidence and perseverance in decision tasks (17).

Symbolic-number Mapping (SMap). The SMap is a 22-question assessment associated with improved ability to discriminate and remember numbers (18). Participants are told to "please draw a 'hatch mark' or little vertical up-and-down line to indicate how big is the number shown" on a scale from 0 to 1,000. On each page, participants place a number on the number line as instructed. As per previously published methods, this measure was reverse scored (i.e., scores closer to 0 represent more exact mapping) on a log scale based on the mean absolute differences between participants' answers and the target number (18). More exact symbolic-numbering mapping is thought to be related to the development of more proficient objective math skills (17).

Patient Activation Measure (PAM). The 13-question PAM has been used to predict outcomes, including healthy behaviors, chronic self-management, maintaining a health/blood pressure diary, controlling chronic illness, and health care costs (8). The PAM has been studied and validated in adults and adolescents; questions assess preventive and health-oriented behaviors, self-management, and health information seeking. Each question is scored on a 4-point scale (1 = disagree strongly, 2 = disagree, 3 = agree, 4 = agree strongly), which are then translated into a 0–100 score. Higher scores represent increased activation.

**Data analysis.** Descriptive statistics were performed. Univariate analysis was performed to identify relations between TRAQ scores and AYA and PG demographic characteristics and other survey scores. Variables with *P* values < 0.05 in univariate analysis were included in multivariate modeling. Using TRAQ scores as the dependent variable, multivariate linear regression models were conducted using backwards, stepwise logistic regression. *P* values less than 0.05 were considered significant. The multivariable analyses did not control for education because education exerts a causal influence on numeric ability.

# **RESULTS**

Ninety-one AYA patients and 54 PGs completed the study. Demographic data and performance on survey instruments are summarized in Table 1. The mean  $\pm$  SD age of AYA respondents was 19  $\pm$  1.3 years. Most patients in this cohort were female (80%), white (78.6%), and had completed some

college/technical school (66.7%), with an additional 26.1% in 12th grade. All annual household income levels were represented, with the plurality (21.5%) in the \$100,000–150,000 range. Among PGs, the mean  $\pm$  SD age was 48  $\pm$  7.9 years and 87% were female. The majority of PGs were white (88.5%) and had completed college or technical school (>60%). All levels of SES were represented in PGs, with \$100,000–\$150,000 being the most common response (26%).

The majority of AYA patients in this cohort (64 of 91) saw a rheumatologist for juvenile idiopathic arthritis (JIA). Four

**Table 1.** Baseline characteristics and survey results for transitioning adolescent/young adults and their parents/guardians\*

	AYA (n = 91)	PG (n = 54)
Age, mean ± SD years	19 ± 1.3	48 ± 7.9
Women	72 (80)	45 (87)
Race		
White	70 (78.6)	46 (88.5)
African American	11 (12.4)	3 (5.8)
Other	8 (9.0)	3 (5.8)
Education		
10th grade	1 (1.5)	0
11th grade	4 (5.8)	0
12th grade	18 (26.1)	9 (16.7)
Some college/tech school	46 (66.7)	12 (22.2)
Graduated college/tech school	0	20 (37.0)
Graduate degree	0	13 (24.1)
Annual household income		
<\$25,000	12 (18.5)	2 (4.0)
\$25,000-\$49,999	11 (16.9)	9 (18.0)
\$50,000-\$74,999	9 (13.6)	10 (20.0)
\$75,000-\$99,999	7 (10.8)	8 (16.0)
\$100,000-\$150,000	14 (21.5)	13 (26.0)
>\$150,000	12 (18.5)	8 (16.0)
TRAQ score, mean ± SD†	$4.0 \pm 0.67$	-
sTOFHLA score, mean ± SD‡	34.1 ± 3.5	$34.7 \pm 1.7$
PAM, mean ± SD§	64.8 ± 17.6	68.0 ± 12.8
SNS, mean ± SD¶	$3.8 \pm 1.1$	$4.0 \pm 1.0$
ONS, mean ± SD#	$3.7 \pm 1.7$	$3.8 \pm 1.7$
SMAP, mean ± SD**	$-0.87 \pm 0.2$	$-0.85 \pm 0.2$

<sup>\*</sup> Values are the number (%) of adolescent/young adults (AYAs) and their parents/guardians (PGs) unless indicated otherwise. TRAQ = Transition Readiness Assessment Questionnaire; sTOFHLA = Short Test of Fundamental Health Literacy in Adults; PAM = Patient Activation Measure; SNS = Subjective Numeracy Scale; ONS = Objective Numeracy Scale; SMAP = Symbolic Number Mapping.

<sup>†</sup> Possible range 1-5.

<sup>‡</sup> Possible range 0-36.

<sup>§</sup> Possible range 0–100.

<sup>¶</sup> Possible range 1–6.

<sup>#</sup> Possible range 0-8.

<sup>\*\*</sup> Possible range -2.14 to 0.

P\*\* Variable† B coefficient‡ b coefficient§ SE¶ t value# 0.00 -0.470.86 -0.55Intercept 0.58 AYA PAM 0.40 0.02 0.003 4.60 < 0.0001 0.33 0.17 0.05 3.72 0.0004 AYA age AYA female 0.22 0.37 0.15 2.49 0.01

Table 2. Final model of predictors of AYA TRAQ scores from AYA surveys\*

patients had lupus, 4 had mixed connective tissue disease, 2 had juvenile dermatomyositis, and the remainder had other conditions, including psoriasis, Behçet's disease, and sclero-derma.

The mean  $\pm$  AYA patient TRAQ score was 4.0  $\pm$  0.67, which reflects an "I am starting to do this" stage of change (12). Most AYA patients (98%) and all PGs had adequate health literacy, as defined by sTOFHLA scores ≥22. Broad concordance existed between AYA patients and PGs on the numeracy measures; average scores of 3.8 and 4.0 (on the 1-6 scale), respectively, were recorded on the SNS. The average score of AYA patients on the ONS was 3.7 and was 3.8 for PGs (out of 8 possible). On the SMap, the average score of AYA patients was -0.87 and -0.85 for PGs. Similarly, the average AYA patient score on the PAM was 64.8, (on a 0-100 scale) signifying "Agree" with items such as, "When all is said and done, I am the person who is responsible for taking care of my health" and "I understand my health problems and what causes them," which is a level 3 score on the PAM (55.2-72.4), indicative of beginning to engage in recommended health behaviors (7,15). The corresponding average score of PGs was 68.0.

In AYA patients, female sex (P = 0.01), older age (P = 0.0004), and higher PAM scores (P < 0.0001) were related to higher transition readiness (TRAQ score) in multivariate regression (Table 2). Results in Table 2 indicated that, for every year increase in age, TRAQ scores increased by 0.17 units.

Table 2 standardized regression results indicated that patient activation was the strongest predictor of AYA patient TRAQ scores, relative to age and sex. Specifically, 1 SD increase in PAM corresponded to a 0.40 SD increase in AYA patient TRAQ scores. Other variables, including scores on the sTOFHLA and numeracy measures as well as demographic data, were not predictive of TRAQ scores in AYA patients. In separate modeling, PG health literacy, numeric competency, and patient activation were not independently associated with AYA TRAQ scores (see Table 3). Higher PG sTOFHLA scores were marginally associated with higher AYA TRAQ scores (P = 0.06). Specifically, 1 SD increase in PG health literacy corresponded with a 0.26 SD increase in AYA patient TRAQ scores.

#### DISCUSSION

To our knowledge, this study is the first to attempt to quantitatively examine transition readiness in the context of AYA and PG health literacy, numeracy, and patient activation. We have shown that AYA patient activation, older age, and female sex predicted higher performance on the TRAQ, whereas other AYA patient characteristics, PG demographics, and other responses did not relate to AYA patient transition readiness in this cohort. The present study also represents the first known study to use the PAM in a pediatric population. Although the measured PG competencies were not significantly associated with AYA transition readiness, certainly

Table 3. Final model of predictors of AYA TRAQ scores from PG surveys\*

Variable†	B coefficient‡	b coefficient§	SE¶	t#	p**
Intercept	0.00	-0.05	2.06	-0.02	0.98
PG sTOFHLA	0.26	0.11	0.06	1.90	0.06

<sup>\*</sup> AYA = adolescent/young adult; PG = parent/guardian; SE = standard error; sTOFHLA = Short Test of Functional Health Literacy in Adults.

<sup>\*</sup> AYA = adolescent/young adult; SE = standard error; PAM = Patient Activation Measure.

 $<sup>\</sup>dagger R^2 = 0.38.$ 

<sup>‡</sup> Coeffient variable = 13.6.

<sup>§</sup> Root mean square error = 0.55.

<sup>¶</sup> Transition Readiness Assessment Questionnaire (TRAQ) score (mean) = 4.03

<sup>#</sup> F value = 16.93.

<sup>\*\*</sup> *P* < 0.0001.

 $<sup>\</sup>dagger R^2 = 0.07.$ 

<sup>‡</sup> Coeffient variable = 18.68.

<sup>§</sup> Root mean square = 0.72.

<sup>¶</sup> Transition Readiness Assessment Questionnaire (TRAQ) score (mean) = 3.86. # F = 3.60.

<sup>\*\*</sup> *P* = 0.06.

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PGs importantly influence AYA beliefs, values, behaviors, and illness experience in many ways that these instruments do not measure.

The association between the PAM and the TRAQ is not surprising because these 2 validated instruments include similar domains. For example, 1 item on the PAM is "I am confident that I can tell a doctor my concerns, even when he or she does not ask"(7). Similarly, TRAQ asks "Do you tell the doctor or nurse what you are feeling?"(12). The strong concordance between these 2 measures is thus reassuring and provides validity to the TRAQ instrument in light of the extensive clinical validation of the PAM (7,8). Higher PAM scores have been linked to improved health behaviors, including seeking preventative care (e.g., cancer screenings, immunizations), healthy eating, exercising regularly, and avoiding smoking. In chronic disease states, highly activated patients have been shown to have better chronic disease control and long-term outcomes, as well as decreased utilization of inpatient and emergency department services and lower health care costs (8).

Importantly, various interventions are effective in increasing adult patient activation. In a study by Hibbard and Greene, these interventions are broadly classified into the following 3 groups: skill development, problem solving, and peer support; changing the social environment; and tailoring support to the person's activation level (8). Skill-based interventions may be community based and rely on teaching patients about specific aspects of disease management, as well as how to communicate effectively with their providers. Often such a program is combined with tailored care, wherein providers use the patient's PAM score to dictate priorities in care and set realistic goals (i.e., smaller steps and more frequent follow-up for less-activated patients). Along these lines, some health care systems have turned to using the PAM as a "vital sign" to be checked regularly to aid clinical decision-making (8). Similar interventions targeted toward transitioning AYA patients can likely improve transition readiness. Using patient activation as a vital sign could help providers to identify patients at increased risk of poor transition outcomes. Further study and use of the PAM in the setting of transition is recommended.

With respect to the associations between older age and female sex on TRAQ scores in AYA patients, these trends support the published developmental literature for adolescents and existing transition literature. Older age and being female are associated with increased self-reported autonomy in pediatric patients, likely allowing those patients to engage more fully in their own medical care (2).

As hypothesized, health literacy and numeracy were not linked to improved TRAQ performance. Nearly every participant in our cohort had adequate health literacy as defined by sTOFHLA ≥23 (11). Our population was largely female, white, and of higher SES and the majority of AYA patients had JIA. Additional study is warranted in other populations in which differences in health

literacy are greater and/or could play a more important role in differentiating those with high and low transition readiness. Indeed, additional data on the roles of health literacy and numeracy could provide actionable guidance for providers on the most effective forms of communication to present health-related information to AYA patients during the transition process, though population-specific effects may exist as noted above.

Our study has several limitations. This small cohort that was enrolled at a single center was racially homogenous and skewed toward white AYA patients (and PGs) who lived in high-income households and were well-educated. Data on education and household income were missing for a substantial number of patients. The cohort's composition may reflect selection bias. Some potential enrollees (both AYA patients and PGs) refused participation when informed that the surveys included completing math problems and a reading test. Thus, numeracy and health literacy scores may be inflated; AYA patients who struggle in math or reading may have been more likely to refuse participation, possibly corresponding to AYA patients of lower education levels and/ or SES. It is not possible to know whether patient refusal affected the sex or racial makeup of the cohort. Our limited ability to enroll PG participants (whether because of their refusal or because the AYA patient was unaccompanied to their medical appointment) restricted statistical power to examine correlations between PG and AYA patient characteristics. Finally, our small study used the TRAQ as a measure of transition readiness. Though clinically validated and widely used as a marker of transition readiness, the TRAQ serves as an imperfect surrogate marker compared to longitudinal data on the actual transition outcomes of these patients. It is our hope that larger, multicenter studies will follow up to examine the validity of our findings (and expand upon them) in more diverse populations, particularly concerning the role of PGs in the transition process.

In conclusion, this study has shown that AYA patient activation, older age, and female sex predict higher TRAQ performance in AYA patients with chronic rheumatologic diseases. In this cohort, no demonstrated association existed between PG demographics or survey performance with AYA patient TRAQ score. Our results identify patient activation as an important modifiable factor in the transition process. Improving patient activation in AYA through targeted interventions represents an opportunity to greatly decrease the morbidity and mortality associated with prolonged transition.

# **AUTHOR CONTRIBUTIONS**

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Lazaroff had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Lazaroff, Peters, Ardoin.

Acquisition of data. Lazaroff, Ardoin.

**Analysis and interpretation of data.** Lazaroff, Meara, Tompkins, Peters, Ardoin.

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