

Association of Transition Readiness to Intentional Self-Regulation and Hopeful Future Expectations in Youth With Illness

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ABSTRACT

BACKGROUND: Little is known about how transition readiness relates to other developmental skills of adolescence in youth with chronic illness. Better understanding of how transition readiness relates to these other developmental skills could lead to a broader array of tools to improve transition readiness. Intentional self-regulation (ISR) and hopeful future expectations (HFE) are 2 developmental skills of adolescence that improve with participation in developmental programming and thus are modifiable.

METHODS: We explored associations between transition readiness, as measured by the Transition Readiness Assessment Questionnaire 29 (TRAQ-29) and ISR and HFE in youth with chronic illness recruited from a variety of subspecialty clinics from a major southeast medical center.

RESULTS: A total of 71 adolescents with chronic illness were included in the analysis. The TRAQ-29 Self-Advocacy domain

showed positive associations to both ISR ($P = .03$) and HFE ($P = .009$). In addition, the TRAQ-29 overall had positive associations to HFE ($P = .04$).

CONCLUSIONS: The significant associations between TRAQ-29 Self-Advocacy domain scores and ISR and HFE suggest that transition readiness is developing within the context of other developmental areas in adolescence. More work is needed to see if the programming that improves these other developmental skills might also improve transition readiness.

KEYWORDS: children with special healthcare needs; hopeful future expectations; intentional self-regulation; transition readiness

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WHAT'S NEW

Transition readiness is associated with intentional self-regulation and hopeful future expectations. It is important to consider the transition process in context of other developmental tasks that adolescents with chronic illness are also experiencing during transition from pediatric to adult-oriented care.

BECAUSE THE TRANSITION from pediatric to adult-oriented care is known to be a vulnerable period for adolescents and young adults with chronic illness,^{1–4} increasing emphasis has been placed on improving care for this population as they make this transition. The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians have jointly published guidelines regarding transition,⁵ which include recommendations to periodically assess transition readiness (ie, ability to effectively function in the adult-oriented healthcare system) in youth throughout the adolescent period. As a result, validated tools to measure transition readiness have been developed.^{6,7}

Little is known about how transition readiness relates to the other developmental processes of adolescence that

youth with chronic illness are also experiencing. To better understand how transition readiness fits in the context of broader youth development, it is important to understand how transition readiness relates to other developmental constructs. If transition readiness were associated with other constructs of youth development, interventions to address these other constructs could be implemented for youth with chronic illness that may then help transition readiness as well.

Intentional self-regulation (ISR), the set of skills aimed at aligning demands and resources to personal goals to achieve better function, is one important construct of general development from childhood to adulthood that helps people to thrive in adulthood.⁸ Higher levels of ISR in early adolescence are associated with higher levels of contribution (such as taking on leadership and service roles) in later adolescence.⁹ Hopeful future expectations (HFE), defined as having a forward-looking set of goals, also leads to more favorable levels of contribution and lower rates of depressive symptoms.¹⁰ Both ISR and HFE are modifiable factors. Participation in youth development programming, such as 4-H clubs, scouting, and Big Brothers Big Sisters is associated with increases in both ISR and HFE.^{9,11,12}

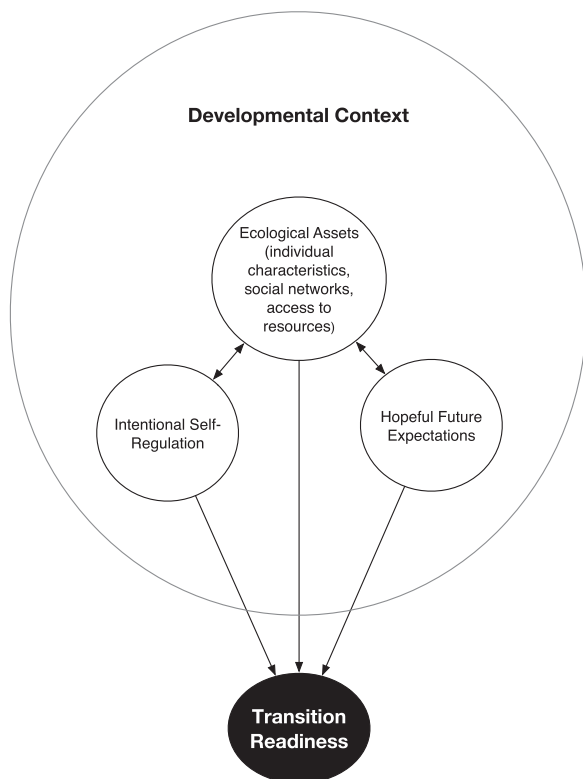


Figure. Model of association between intentional self-regulation, hopeful future expectations, and transition readiness.

For this analysis, we hypothesized that higher levels of transition readiness are associated with higher levels of ISR and HFE. These hypotheses are based on evidence that 1) transition readiness and ISR are both involved in the adaptation of goals according to the needs of the environment^{8,13} and 2) a belief that HFE can serve as a motivation to develop transition readiness just as it motivates the development of ISR.¹⁴ The Figure delineates the theoretical model, which is adapted from the Lerner model describing factors leading to the thriving of youth in adolescence.¹¹

METHODS

POPULATION

This is an analysis of survey data originally collected to examine positive youth development in youth with chronic illness. In the original study, a convenience sample of English-speaking youth aged 13 to 18 with a chronic illnesses (cystic fibrosis, congenital heart disease, sickle cell disease, inflammatory bowel disease, lupus, juvenile inflammatory arthritis, muscular dystrophy, cancer survivor, and seizure disorder) was recruited between 2013 and 2015 when participants presented for a clinic visit with their respective pediatric specialist at a major southeast medical center.¹⁵ Eligible youth were approached by trained research staff, and consent was obtained from parents of participants aged 13 to 17 years or from the participants themselves when they were aged 18 years. Youth completed surveys independently either while waiting in

the clinic or online after their clinic visit. Of the 237 children with chronic illness enrolled, 174 completed the study survey (73% response rate). Subjects were dropped from the final analysis if they had incomplete data on the Transition Readiness Assessment Questionnaire 29 (TRAQ-29) ($n = 97$), HFE ($n = 0$), or ISR ($n = 6$). The final analytical sample consisted of 71 youth with complete (ie, nonmissing) data across the TRAQ-29, HFE, and ISR questionnaires.

Participants were compensated for study enrollment, and the protocol was approved by the Duke institutional review board.

The study used a noncategorical approach rather than a condition-specific one. Previous work has found that experiences are not substantially different across diagnoses and that there are commonalities due to the presence of any chronic condition.¹⁶ Thus, a noncategorical approach is appropriate for this study.

MEASURES

TRANSITION READINESS

The previously internally validated TRAQ-29 was used as the measure of transition readiness. It consists of 29 items divided into 2 domains (Self-Management and Self-Advocacy). The measure was developed to assess transition readiness in youth without regard to a specific diagnosis and was found to be reliable, with a Cronbach's alpha value of 0.92 for Self-Management and 0.82 for Self-Advocacy when studied in adolescents and young adults (aged 16–26 years) with chronic illness.⁶ Answers are recorded on a 5-point Likert scale, and the final score is a mean of the items, ranging from 1 to 5, with higher scores indicating more transition readiness. In the validation work, each 1-year increase in age was associated with a 0.12-point increase in TRAQ-29 Self-Management domain and a 0.03-increase (nonsignificant) in the Self-Advocacy domain.⁶ Since the dissemination of the survey, the TRAQ-29 has been reduced to the TRAQ-20.⁷ Due to differences in scoring systems and factor structures, the 2 tools are not interchangeable. Thus, we used the TRAQ-29, the transition readiness measure that we had, for this analysis.

INTENTIONAL SELF-REGULATION

ISR was measured using a validated adaptation of the tool developed by Freund and Baltes¹⁷ for use in adults. The tool, which was initially developed in Germany, was refined for use in children and adolescents to a 9-item scale, which was found to be fairly reliable in American adolescent populations (Cronbach's alpha 0.63).^{18–20} Each item in the scale is a choice between 2 options. For example, one pairing is, "I think about exactly how I can best realize my plans" versus "I don't think long about how to realize my plans, I just try it," and participants choose the answer that better describes them. In this example, the first option would indicate more self-regulation. The final scale score is sum of the responses, with a range of scores from 0 to 9; higher scores are associated with more ISR.

HOPEFUL FUTURE EXPECTATIONS

HFE was measured using a 13-item scale developed for the 4-H Study of Youth Development. For each item, youth were asked to rate on a 5-point Likert scale how likely they were to complete certain tasks, such as graduating from high school, getting married, and having a job, with 1 being not at all likely and 5 being very likely. Previous work has shown this scale to have high reliability in teenagers, with Cronbach's alpha of 0.94, 0.95, and 0.95 for youth in grades 7, 8, and 9 respectively.¹⁰ The final scale score is a mean of the items in the scale, with a range of 1 to 5 and higher scores indicating a higher degree of HFE. Iovu et al²¹ showed that the items of the HFE measure, although focused on global optimistic life events, are significantly correlated with other measures of optimism.

SOCIOECONOMIC STATUS

For this article, socioeconomic status (SES) was measured using the household crowding index, which is calculated by taking the number of people in a home and dividing it by the number of bedrooms in the home. It has been shown to be a reliable indicator of SES and is more accurately reported by youth than household income.²² For this index, higher scores indicate lower SES, as it means that there are more people in each bedroom of the house.

OTHER VARIABLES

We collected demographic variables, including participant's age, biological sex, race, and chronic condition. We also collected youth self-report of whether they had a documented learning disability or physical disability.

DATA COLLECTION AND MANAGEMENT

Study data were collected and managed using REDCap electronic data capture tools hosted at Duke University.²³ REDCap (Research Electronic Data Capture) is a secure, Web-based application designed to support data capture for research studies.

ANALYSIS

Complete case analysis was chosen to minimize bias from the use of incomplete responses. We did not perform a power calculation, as this was a secondary data analysis and retrospective power calculations have statistical flaws.²⁴

We initially examined the characteristics of the sample to determine distribution of variables and to look for missing data. Means and standard deviations were calculated for continuous variables, and frequencies were calculated for categorical variables. Comparisons between those with complete data and those with missing data on the measures were also done to assess risk of bias from the use of a complete-case analysis strategy.

We made the a priori decision to assess for possible confounding due to age, gender, learning disability, SES, and physical disability. Older age^{6,25} and female gender^{6,26} were chosen because in the literature, they are associated

with higher levels of transition readiness. Intellectual disability appears to be associated with less transition readiness,²⁷ so we included the presence of a learning disability as a marker of intellectual difficulties. SES and physical disability were also included because models suggest that they influence transition readiness as well.¹³ We performed bivariate analyses assessing the association between these possible confounders and the TRAQ-29 scores. We also assessed the unadjusted association between ISR and TRAQ-29 scores, and HFE and TRAQ-29 scores.

Finally, to determine the best model fit, we used linear regression to evaluate the associations between transition readiness and ISR as well as the associations between transition readiness and HFE, adjusted for the confounders assessed previously. We used a change-in-effect method to determine which possible confounders could be dropped, leaving only those variables that resulted in a more than 10% change in association estimates.²⁸ As a result, the final model adjusted for age, gender, and the presence of a learning disability.

Because this was an exploratory study, we did not make adjustments for multiple comparisons, as this increases the likelihood of a Type II error,²⁹ which could potentially cut off important avenues of research prematurely while still in an exploratory phase.

All analyses were performed by Stata 14 software (StataCorp, College Station, Tex). Significance level was set at $P < .05$.

RESULTS

The average age of the group was 15.4 years (Table 1). The group was 46% male and had a generally even distribution across the diagnoses included.

The overall response rate on the survey was 73%. However, because of our decision to use complete case analysis, only 71 of 174 who responded were included in the analysis. In comparisons of the included and excluded responders, the groups were found to be generally similar with regard to demographic variables, ISR scores, and HFE scores (Table 1). The excluded group had a higher TRAQ-29 overall mean (3.5 for those included and 3.9 for those excluded) and a higher TRAQ-29 Self-Management domain score (3.1 for those included and 3.5 for those excluded). This suggested that exclusion of those with incomplete data would result in a bias toward the null.

In the bivariate analyses, shown in Table 2, age, gender, and the presence of a learning disability had significant associations with TRAQ-29 scores, while SES and physical disability were not significantly associated.

Table 3 shows the unadjusted and adjusted associations between the TRAQ-29 total score and domain scores versus ISR and HFE. Only the association between the TRAQ-29 Self-Advocacy domain and HFE was significant before adjusting for possible confounders. The associations that were significant after adjusting for age, gender, and learning disability were TRAQ-29 Self-Advocacy score and ISR ($P = .03$), overall TRAQ-29 score and

Table 1. Characteristics of Included and Excluded Responders

Characteristic	Included Responders (n = 71)	Excluded Responders	No. of Excluded Responders With Data*	P
Age, mean (SD)	15.4 (1.6)	15.1 (1.7)	103	.26
Male gender, %	46	46	103	.91
Race, %			103	.37
White	63	52		
Black	28	38		
Hispanic	3	6		
Other	6	4		
Household crowding index, mean (SD)	1.3 (0.5)	1.2 (0.5)	95	.24
Condition, %			103	.22
Cystic fibrosis	11	7		
Congenital heart disease	10	12		
Diabetes	15	16		
Inflammatory bowel disease	11	15		
Muscular dystrophy	8	1		
Seizures	10	15		
Cancer survivor	7	9		
Lupus	13	18		
Sickle cell	14	8		
Physical disability			99	.81
Yes	20	21		
No	80	79		
Learning disability			99	.78
Yes	14	17		
No/don't know	86	83		
ISR score	4.2 (1.1)	4.2 (1.2)	85	.92
HFE score	4.4 (0.6)	4.3 (0.5)	89	.62
Overall TRAQ-29 score	3.5 (0.8)	3.9 (0.9)	84	.02
TRAQ-29 Self-Management score	3.1 (1.0)	3.5 (1.2)	82	.048
TRAQ-29 Self-Advocacy score	3.9 (0.8)	4.0 (0.9)	80	.22

HFE indicates hopeful future expectations; ISR, intentional self-regulation; and TRAQ-29, Transition Readiness Assessment Questionnaire 29.

*Out of a possible 103.

HFE ($P = .04$), and TRAQ-29 Self-Advocacy score and HFE ($P = .009$). The TRAQ-29 overall score was not associated with ISR. Neither ISR nor HFE was associated with the TRAQ-29 Self-Management domain.

DISCUSSION

This study found a positive association between TRAQ-29 Self-Advocacy scores and ISR and HFE scores after adjustment for age, gender, and the presence of a learning disability. There was also an association between TRAQ-29 score overall and HFE after adjustment for age, gender, and the presence of a learning disability. Both our study and previous work⁶ with the TRAQ-29 have shown an association of a 0.1-point change in TRAQ-29 domain scores for every 1-year increase in age. Thus, a 1-point increase in

ISR or HFE has a similar or larger association to TRAQ-29 Self-Advocacy scores as a 1-year increase in age.

With this study, we can begin to consider transition readiness and its relationship to the other developmental processes of adolescence. Rather than consider transition readiness as a separate process for youth with chronic illness, we examined how transition readiness and other facets of adolescent development are related. This study suggests that higher levels of development skills are generally tied to higher levels of transition readiness. Thus, encouraging positive development generally in youth with chronic illness may improve their transition readiness as well, though further work will be needed to show this definitively. Providers who care for youth with chronic illness can consider encouraging youth with chronic illness through the developmental tasks of adolescence just as they would for youth without chronic illness, including

Table 2. Bivariate Associations of TRAQ-29 Scores and Confounders

Characteristic	β Estimate for TRAQ-29 Mean (95% CI)	P	β Estimate for TRAQ-29 Self-Advocacy (95% CI)	P	β Estimate for TRAQ-29 Self-Management (95% CI)	P
Age	0.13 (0.01 to 0.25)	.03	0.16 (0.05 to 0.27)	.004	0.10 (−0.05 to 0.25)	.17
Gender	0.5 (0.13 to 0.89)	.01	0.51 (0.17 to 0.86)	.004	0.51 (0.04 to 1.0)	.04
Socioeconomic status	−0.01 (−0.43 to 0.41)	.95	−0.09 (−0.48 to 0.30)	.64	0.05 (−0.46 to 0.57)	.84
Physical disability	−0.08 (−0.58 to 0.42)	.74	−0.11 (−0.57 to 0.35)	.63	−0.09 (−0.71 to 0.53)	.77
Learning disability	1.1 (0.59 to 1.61)	<.001	0.8 (0.31 to 1.30)	.002	1.35 (0.73 to 1.98)	<.001

CI indicates confidence interval; and TRAQ-29, Transition Readiness Assessment Questionnaire 29.

Table 3. Unadjusted and Adjusted Associations Between TRAQ-29 and HFE, and TRAQ-29 and ISR

Analysis	Unadjusted β	Adjusted β (95% Confidence Interval) [†]
TRAQ-29 and ISR	0.16	0.10 (−0.06 to 0.26)
Self-Management and ISR	0.11	0.05 (−0.15 to 0.26)
Self-Advocacy and ISR	0.22	0.16 (0.02 to 0.31)*
TRAQ-29 and HFE	0.26	0.33 (0.02 to 0.65)*
Self-Management and HFE	0.21	0.24 (−0.18 to 0.65)
Self-Advocacy and HFE	0.27**	0.39 (0.10 to 0.68)**

HFE indicates hopeful future expectations; ISR, intentional self-regulation; and TRAQ-29, Transition Readiness Assessment Questionnaire 29.

* $P < .05$.

** $P < .01$.

[†]Adjusted for age, gender, and presence of learning disability.

encouragement in developmental programming, such as 4-H and Big Brothers Big Sisters. Clinicians may also consider utilizing the HEADSS (home, education, activities/employment, drugs, suicidality, and sex) assessment recommended for all adolescents³⁰ as a tool in providing transitional care to youth with chronic illness. The education and activities/employment sections, the “EA” in HEADSS, elicit a youth’s future expectations, and the associations found in this study suggest that higher expectations in these domains may be associated with higher transition readiness. Thus, the HEADSS assessment can augment any transition readiness assessments that providers are already doing in their offices.

Previous models have considered the contribution of adolescent and young adult characteristics in the success of transition, with an emphasis on modifiable factors.¹³ This study begins to explore ISR and HFE as specific modifiable factors to target for improving transition readiness and refine our understanding of transition readiness and the factors that contribute to successful transition from pediatric to adult-oriented care. ISR and HFE are especially notable as possible modifiable factors contributing to successful transition because participation in out-of-school programs (ie, Big Brothers Big Sisters) has been shown to increase ISR and HFE.^{9,11,12} If future studies can demonstrate a stronger link between program participation and improvements in ISR, HFE, and transition readiness, this would further build the evidence base to encourage participation in developmental programming for youth with chronic illness.

We used the TRAQ-29 rather than the newer TRAQ-20 for this study. Most of our results showed associations with the Self-Advocacy domain of the TRAQ-29, which was refined into 3 domains in the TRAQ-20: Talking With Providers, Managing Daily Activities, and Tracking Health Issues.⁷ We suggest that further studies looking to explore the associations between ISR and HFE focus on these domains.

This study is limited by a small sample size and the use of complete case analysis. The number of adolescents included in this analysis ($n = 71$) was much smaller than the number of participants who submitted the survey ($n = 174$). We chose a complete case analysis approach because we were performing exploratory research in a

new area, and so wanted to minimize bias introduced by including those with incomplete responses in this analysis. We assessed for the risk of bias introduced by this analysis decision and found that those excluded had higher TRAQ-29 scores and similar ISR and HFE scores to those included, suggesting that bias would be toward the null. As to why so many participants did not complete the TRAQ-29, this measure was near the end of the survey, which suggests that testing fatigue, a common phenomenon in adolescent populations, resulted in the low completion rate.³¹

The study is also limited in that it only compared transition readiness to 2 other developmental constructs, ISR and HFE. Other constructs and measures may have stronger relationships to transition readiness, but these were not assessed here. The study is limited by the fact that it uses cross-sectional data, so cause and effect cannot be directly established. We used self-report as our measure of the presence of a learning disability, which may not be entirely accurate. However, those with a self-reported learning disability did have a lower TRAQ-29 score in the bivariate analysis, suggesting that the use of self-report was reasonably accurate in this data set.

Despite the study’s limitations, this work opens up a new and important line of inquiry in the integration of transition readiness into the other realms of youth development for adolescents and young adults with chronic illness.

CONCLUSIONS

This study shows statistically significant associations between transition readiness and ISR and HFE, suggesting that transition readiness may be developing within the context of other developmental constructs for adolescents and young adults with chronic illness. It presents a new avenue to consider more extensively how to improve transition readiness within a larger developmental context, possibly through programming that has already been shown to enhance youth development.

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