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]

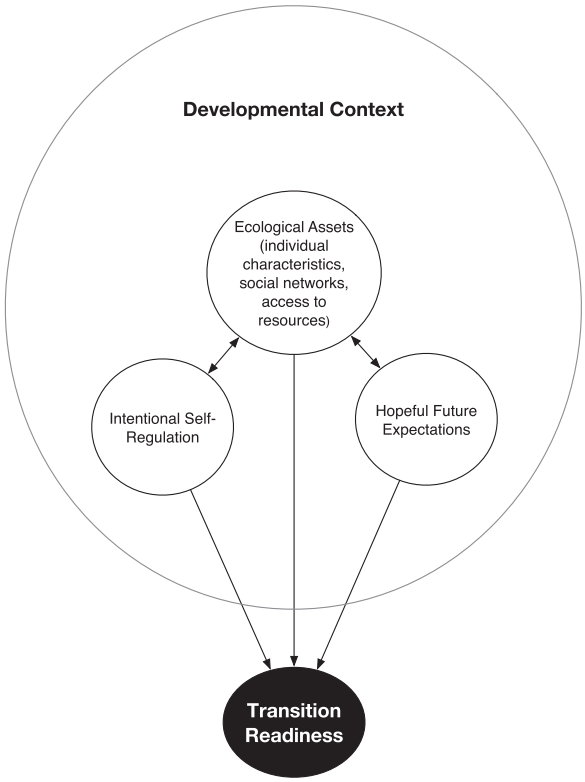

Figure. *Model of association between intentional self-regulation, hopeful future expectations, and transition readiness.*

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 Baltes[17] 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.