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A mixed methods exploratory study assessing youth knowledge, self-efficacy and mental health outcomes in transition to adult healthcare

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ABSTRACT

Background: Transition from adolescence to adulthood is a change in status yielding self-sufficiency, independence, and participation in adult roles. There are numerous efforts to define transition elements and encourage formalized processes readying youth for adulthood, yet significant challenges remain.
Methods: We recruited individuals who were age 12 years or older and not transitioned or 18 years and older who transitioned within 24 months to complete questionnaires and participate in a focus group.
Results: 25 participants (Mean age 17.9 years) completed questionnaires and 76 % participated in focus groups. Youth 18 years and older had mean scores in the reason for concern range on 7 of 9 NIH Toolbox scales de. Transition readiness was lower in adults across all five categories. Key themes include misunderstanding the concept of transition and self-determination in transition.
Conclusions: Few youth understood what “transition” entails. Most considered it a single issue, such as aging out of insurance or leaving their pediatric specialist. Youth self-efficacy and life outlook declines in the late teens and early adulthood, exacerbating perceived inability to self-manage and gain independence. Most concerning is the emotional well-being and self-esteem of our adults who scored in the reason for concern range in 7 of 9 scales whereas adolescent peers did not. A directed attempt to create self-efficacy for youth in transition through training in health management, understanding the meaning of transition and promoting a positive perception prior to transition is needed.

1. Introduction

Transitioning individuals with pediatric onset chronic illness to adult health care has been a topic of national significance for over a decade and adolescent health was included in both US Department of Health and Human Services (US DHHS) Healthy People 2020 and 2030.[1,2] Transition from adolescence to adulthood is a process identifying a change in status that yields self-sufficiency, independence, social participation and taking on adult roles.[3] The definition of adult varies in society and across medical disciplines, however the standard for primary care is between 18 and 21 chronological years of age regardless of developmental maturity and skills or ability to be autonomous and navigate new systems independently.[4]

There are numerous efforts by various medical specialty academies and government agencies to define the elements of transition and encourage clinical practices to engage in formalized processes readying youth in their care for adulthood yet significant challenges remain and US DHHS is considering creating transition to adult care as a core objective (see AH-R01).[5–8] Youth experiences during transition to adulthood are bipolar as the prospect of becoming an adult is exciting but they feel ill-equipped and unsupported while learning their adult roles.[9] Similarly, they feel like they are treated not quite like adults during their engagement and decision-making while being required to meet adult expectations.[9] Adult practitioners are not equipped to manage individuals who are chronologically adult but still lack the developmental maturity to be fully independent, deeming them to be not prepared.[10–12]

Transition programs have been shown to improve the transition process and encourage youth to stay in care but there is a financial burden of these programs in the maintenance of dedicated staff who are

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unable to bill for their time and are not sustainable for many smaller practices.[13,14] Much of the onus of transition is placed on the pediatric practitioners' shoulders. However, positive youth development demonstrates creating a safe environment for adolescents to mature and obtain skills yields the best results in transitioning to adult behaviors and decision-making, which cannot be restricted to the pediatric environment.[12,15–18] Lastly, data has shown that maintenance of care is only one factor in a more complex social-ecological model of well-being and transitioning an individual into adulthood is far more complicated than transitioning just one aspect of their needs, such as switching to an adult-focused healthcare provider.[19–21] Providing youth the ability to act in a self-directed manner and the tools needed in a safe, learning environment leads to engagement and ultimately successful transition into adult roles.[9,15]

We collected standardized scales, medical record data and conducted a series of focus groups with adolescents with a variety of health care needs between the ages of 12- and 24-years about their understanding, ownership, readiness and feelings toward transitioning to assess the level of engagement of youth and barriers experienced in their own transition to adulthood with the intent of developing a youth-approved approach to transition preparation.

2. Materials and methods

2.1. Setting and recruitment

We recruited individuals from various local clinics and through social media campaigns who are age 12 years or older and indicate that they have not transitioned to adult care (transition age ranges by practitioner from 18 – 24 years of age) and those 18 years and older who report that they have transitioned to adult care within the previous 24 months. We sought a wide range of conditions that fell into the following four categories: (1) "visible" disabilities which include observable physical deformities or impairments; (2) "invisible" disabilities including both non-observable conditions or physical impairments that can be hidden; (3) behavioral or intellectual disabilities which tend to conflict with societal norms; and (4) "terminal" conditions that could encompass any of the three previous categories but have the added burden of a reduced lifespan. Individuals were excluded if there was a documented inability for self-care either through legal guardianship status or behavioral and intellectual impairments that reduce cognition below moderate intellectual impairment defined as intelligence quotient levels of 35–55. All individuals consented to participate in the two parts of the study, if they were under the age of 18 their parents also consented allowing their child to participate. The intent of the funding was to explore the feasibility of assessing transition from the youth perspective to generate preliminary results within a short time frame.

The study was approved by an Institutional Review Board under protocol number # STUDY00001205.

2.2. Measures

Pierce and Wysocki (2015) described an expanded Social-Ecological Model of Adolescents and Young Adult Readiness for Transition (SMART) with the pre-existing factors and modifiable variables that directly contribute to an individual's readiness to transition and how that readiness and the pressure of external systems influences their clinical outcomes, health promotion behaviors, and emotional well-being.[14] A subsequent study identified key stakeholder outcomes relating to facilitated navigation of health care systems, integration of disease management into adult roles and autonomy in ownership of self-management.[22] We adapted the expanded SMART model to include the identified stakeholder outcomes, an overlay of the Positive Youth Development Framework lens and selected measurement tools for quantitative data collection (Fig. 1).[22,23]

2.2.1. Demographics questionnaire

We included a basic demographics questionnaire asking about participant gender, race, current grade in school or last grade completed, enrollment in special education, primary insurance, diagnoses, the number of doctors they are currently seeing, and the number of medications prescribed. Medical data were confirmed through medical record abstraction when possible and condition severity and functional status listed in the last documented note were coded.

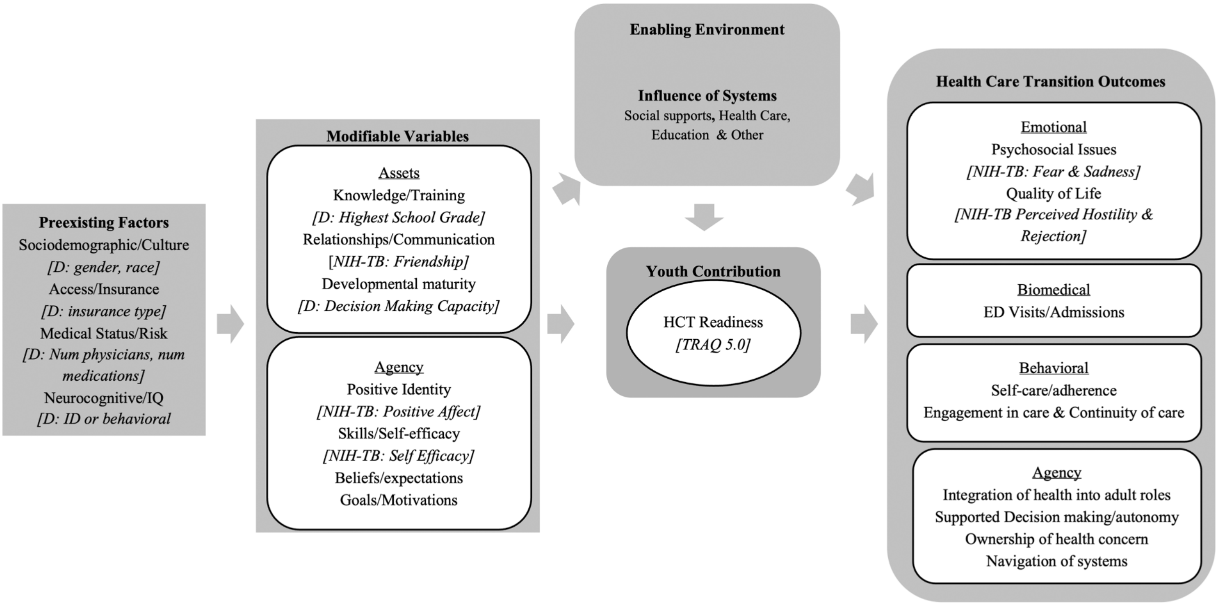

Fig. 1. An Adaptation of the Expanded Social-ecological Model of AYA (adolescents and young adults) Readiness for Transition Model, Overlaid with the Positive Youth Development Model and Selected Measurement Tools. D: Demographics questionnaire; NIHTB: NIH Toolbox® for Assessment of Neurological and Behavioral Function (NIH Toolbox) Emotion Batteries; AEFI: Amsterdam Executive Function Index; TRAQ: Transition Readiness Assessment Questionnaire.

2.2.2. *NIH toolbox® for assessment of neurological and behavioral function emotion batteries*

We selected NIH Toolbox (NIHTB) Emotion Battery Items for use in measuring emotion related assets, agency and emotional status. All NIHTB results are reported as an uncorrected T-score with a mean of 50 and standard deviation of 10 standardized to the US General Population.[24] For measures assessing positive factors, a T score < 40 is considered a potential concern and for measures assessing negative factors a T-Score of > 60 is of potential concern.[25] Each scale is answered on a 5-point Likert scale ranging from 1 – 5, unless indicated. Scales for adolescents (through age 17) and adults (18 +) were used based on respondent's age at survey. Selected measures for modifiable variables include Positive Affect Bank/Fixed Form v2.0; Self-Efficacy Bank/Fixed Form v2.0; Friendship Fixed Form v2.0; Perceived Stress Bank/Fixed Form v2.0; Anger/Anger - Affect Fixed Form v2.0. Measures for outcomes include Perceived Hostility Fixed Form v2.0; Perceived Rejection Fixed Form v2.0; Loneliness Fixed Form v2.0; Sadness Fixed Form v2.0; Fear/Fear - Somatic Arousal Fixed Form v2.0.

2.2.3. *Transition readiness assessment questionnaire (TRAQ) 5.0*

TRAQ was selected for this study as the only psychometrically validated, disease-agnostic transition assessment.[26] TRAQ has 20 questions on a 5-point Likert scale with 5 subscale scores and total overall score. Subscale scores address medication management, keeping appointments, tracking health, talking with providers and managing activities of daily living.[27]

2.2.4. *Amsterdam executive function index (AEFI)*

AEFI is a brief self-report tool assessing risk for executive function deficits in three areas: Attention, Self-Control and Self-Monitoring, and Planning and Initiative.[28] There are 13 questions answered on a 3-point Likert scale. Results are normed to education level and gender. We assumed an average level of education across all our participants. Scores are reported as % of the population performing at or below participant performance.

2.2.5. *Youth decision-making competence (YDMC)*

The YDMC measures seven components contributing towards young adult competency and decision-making capacity.[29] Due to the length of the scale, we only included the 16 questions of the recognizing social norms component as the remaining scale items would likely require coaching for our younger participants and the questionnaire was sent out as an asynchronous questionnaire. The questionnaire is scored across all subjects to establish the group norms (% yes) and then each individual is compared to the group using Spearman correlations resulting in a score between -1 and 1. In addition, we included four yes/no questions related to concepts typically addressed in directed clinical interviews to assess an individual's capacity to make an informed medical decision.[30]

2.2.6. *Focus groups*

Participants were scheduled for focus groups by age (12 – 14; 15 – 18; 18 +) plus transition status (Yes -No transitioned to adult care) for the 18 + groups. Groups with 12 – 14-year-olds scheduled for 30 – 45 minutes and 1 – 1.5 h for 15 years and up. Focus groups occurred via zoom and were recorded. Verbal responses were transcribed and direct chat text were embedded chronologically into a transcript. The initial intent of the focus groups was to create a quantitative pathway on the positive and negative aspects of the transition journey using fuzzy cognitive mapping approaches. It became evident in the initial focus group that few participants understood the transition process, what it entailed and what ultimately transitioning into adult models of care actually meant. As such, we revised the focus group agenda to focus more on shared responsibility and participant feelings about decision-making and self-advocacy. Participants were asked to describe what they believed transition entailed, then after showing them the transition timeline with activities from Got Transition® (Fig. 4) they were asked to talk about their current transition status specific to those activities and the types of tasks they do, what they are comfortable taking on and when they believe they should be fully transitioned. Participants were also asked about decision-making practices and how conflicts were resolved

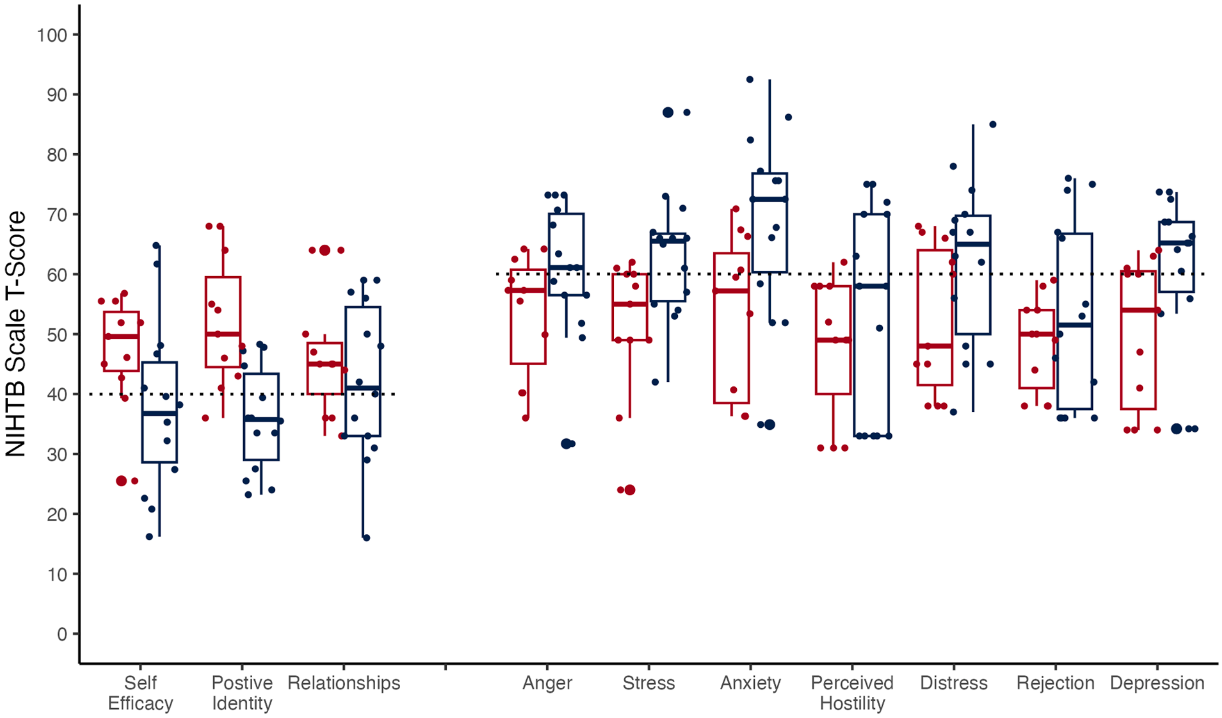

Fig. 2. Adolescent and Adult scores on NIHTB Emotion Battery Scales for Expanded SMART modifiable variables representing positive traits on the left demonstrating reason for concern for scores below the demarcation (T-Score 40) and negative traits the right demonstrating reason for concern for scores above the demarcation (T-Score 60).

with their parents. These questions roughly map to the behavioral and agency outcomes in Fig. 1. Lastly, we asked what types of things would encourage them to transition and whether or not they felt ready to take responsibility for the transition activities specific to their age. All responses in this manuscript represent naturalized transcription removing spacers, repetitions and grammatical errors. Participants were given the opportunity to review this manuscript and quotations. The focus group lead was unaffiliated with the research team and indicated such in the focus groups.

2.3. Statistical analysis

We compared individuals under age 18-years (youth) and 18-years or older (adults) using chi-square tests for categorical variables. Normality of continuous variables by group were assessed with the Shapiro-Wilks Test. Normally distributed variables were assessed with a *t*-test if both groups were normally distributed, otherwise comparisons were made using Wilcoxon rank sum. NIHTB scales were compared on both the mean T scores as well as the proportion of the group scoring as 'reason for concern.' A p-value of less than.05 was considered significant. Focus group results were interpreted using the Rabiee (2004) framework analysis which involves assessing individual participant statements in context of the overarching question being asked and looking for internal consistency within participant points of view, determining the extensiveness and frequency of response patterns within and across focus groups when determining themes, use of responses that are specific examples rather than hypothetical statements, and tying everything into a big picture. In addition, the focus group moderator summarized their observations and provided an independent big picture assessment with key take home points.[31] All data were analyzed in R.[32]

3. Results

Baseline demographics and clinical characteristics of the two cohorts are reported in Table 1. A total of 25 individuals completed the questionnaires, just over half (14/25, 56 %) of whom were aged 18 years or older. There are no statistically significant group differences in the distributions for the pre-existing factors listed in Fig. 1 (Table 1) with the logical exception of age. We were able to confirm reported medical information in 52 % (13/25) of cases, the remaining received care in medical systems for which we did not have direct access.

The Expanded SMART model includes modifiable variables representing skills and beliefs that can improve or detract from youth health care transition readiness. These modifiable variables include assets provided and a youth's perception of agency in gaining readiness skills. There were no statistical differences in any of the assets between the groups other than level of education. The adults had all completed or were completing 12th grade, whereas the youth were split between middle school or grades 7 – 9 and high school or grades 10–12. Recognition of social norms was similar across the individuals and the majority of participants demonstrated sufficient decision making capacity (75 % or higher) to participate and have a voice in decisions regarding their care(Table 1). The overall executive functioning was highly variable across the participants and in general their scores were below the 50th percentiles compared to age-matched normative data (Fig. 2).

Agency modifiable variables did demonstrate significant differences between the groups. The adult group had significantly higher proportions scoring in the reason for concern range for positive identity (NIHTB Positive Affect), self-efficacy and stress compared to their younger peers (Table 2). Mean group T-scores were significantly reduced for positive affect and significantly elevated for stress in adults as compared to children (Table 2, Fig. 3). Furthermore, the adult group had mean agency scores demonstrating reason for concern in all four scales (Table 2, Fig. 3).Youth contribution, or transition readiness did not differ between age groups despite the significant mean age difference between the two groups.

Table 1
Pre-existing factors for participants by age group.

	Total N = 25	< 18 years N = 11	≥ 18 years N = 14	p. overall
Age at Focus Group M (SD)*	17.9 (4.54)	14.2 (2.18)	21.5 (2.94)	< 0.001
Gender				0.13
Male	14 (56.0 %)	4 (36.4 %)	10 (71.4 %)	
Female	8 (32.0 %)	4 (36.4 %)	4 (28.6 %)	
Other	3 (12.5 %)	3 (27.2 %)	—	
Race/Ethnicity				0.36
Non-Hispanic White	12 (46.2 %)	5 (45.5 %)	7 (46.7 %)	
Hispanic	7 (26.9 %)	4 (36.4 %)	3 (20.0 %)	
Other	7 (28.0 %)	2 (18.1 %)	5 (35.7 %)	
Type of insurance				0.10
Private	2 (7.69 %)	1 (9.09 %)	1 (6.67 %)	
Public	16 (61.5 %)	9 (81.8 %)	7 (46.7 %)	
Other	8 (30.8 %)	1 (9.09 %)	7 (46.7 %)	
Special Education in School				1.00
No	9 (37.5 %)	4 (36.4 %)	5 (38.5 %)	
Yes	15 (62.5 %)	7 (63.6 %)	8 (61.5 %)	
Intellectual Disability or Behavioral Disorder				0.36
No	21 (80.8 %)	10 (90.9 %)	11 (73.3 %)	
Yes	5 (19.2 %)	1 (9.09 %)	4 (26.7 %)	
Participated in Focus Group				0.18
No	6 (24.0 %)	1 (9.09 %)	5 (35.7 %)	
Yes	19 (76.0 %)	10 (90.9 %)	9 (64.3 %)	
Number Specialists Mdn [95 % CI]	2.00 [1.00;5.75]	2.00 [1.00;6.50]	3.00 [1.50;5.00]	0.71
Number Medications Mdn [95 % CI]	3.00 [1.00;5.00]	2.00 [0.50;4.50]	3.00 [1.50;5.50]	

N = Number, M = Mean; s = standard deviation; Mdn = Median; CI = confidence interval

The adult group had significantly higher proportions scoring in the reason for concern range perceived rejection compared to their younger peers (Table 2). Mean group T-scores were again significantly elevated for three of the five outcomes in adults as compared to children (Table 2, Fig. 3), specifically somatic anxiety (NIHTB Fear M=69.0, 71.4 %), depression (NIHTB Sadness M=61.2; 71.4 %) and distress (NIHTB Loneliness M=61.9, 54.3 %).

3.1. Focus group themes

19 of the 25 participants attended a focus group; 84 % of those participating had a primary or comorbid behavioral disorder and 32 % of whom had an invisible condition (Table 3). Two other individuals participated in focus groups but did not complete most of the scales so were excluded from quantitative analyses. Table 4 provides an overview of quotes by focus group themes.

3.1.1. Theme 1: (Mis)understanding transition

In general, most of the individuals participating in the focus groups did not have a complete picture of transition. Everyone understood the individual components, and all agreed with the general progression proposed by Got Transition® (Fig. 4), but they did see all these pieces as their adult roles when transitioned. Only two individuals mentioned an understanding of their caregiver's mortality and the need to be independent as a result. Most associate the term 'transition' with a single issue or concern like financial independence related to ability to pay for healthcare needs or finding an adult provider.

Table 2
Modifiable Variables, transition readiness and outcomes of participants by age group. bolded items are within the reason for concern range for scales.

	Total **N = 25**	< 18 years **N = 11**	≥ 18 years **N = 14**	p. overall
Modifiable Variables - Assets				
Relationships (NIHTB Friendship†)				
Reason for Concern N (%)	9 (36.0 %)	3 (27.3 %)	6 (42.9 %)	0.68
T-Score M(s)	43.9 (11.9)	46.3 (10.2)	42.1 (13.2)	0.38
Decision-Making Capacity (Yes)				1.00
≤ 25 % Capacity	2 (8.33 %)	1 (9.09 %)	1 (7.69 %)	
50 % Capacity	1 (4.17 %)	0 (0.00 %)	1 (7.69 %)	
75 % Capacity	9 (37.5 %)	4 (36.4 %)	5 (38.5 %)	
100 % Capacity	12 (50.0 %)	6 (54.5 %)	6 (46.2 %)	
Social Norms Mdn [95 % CI]	0.44 [0.39;0.53]	0.42 [0.41;0.43]	0.50 [0.33;0.57]	0.37
Grade in School				< 0.001
7th – 9th	5 (20.0 %)	5 (45.5 %)	0 (0.00 %)	
10th – 12th	17 (60.0 %)	6 (54.5 %)	9 (64.3 %)	
Completed	5 (20.0 %)	0 (0.00 %)	5 (35.7 %)	
Executive Functioning				
Planning & Initiative Mdn [95 % CI]	43.0 [10.0;78.0]	78.0 [26.5;78.0]	16.5 [8.50;55.8]	0.27
Attention Mdn [95 % CI]	30.0 [3.00;56.0]	56.0 [8.00;66.5]	28.0 [3.00;54.0]	0.29
Self-Control/ Management Mdn [95 % CI]	14.0 [1.00;40.0]	25.0 [1.00;48.5]	14.0 [2.00;25.0]	0.89
Modifiable Variables - Agency				
Positive Identity (NIHTB Positive Affect†)				
Reason for Concern N (%)	11 (44.0 %)	1 (9.09 %)	10 (71.4 %)	< 0.01
T-Score M(s)	43.0 (12.6)	52.1 (10.9)	**35.9 (8.8)**	< 0.01
NIHTB Self-Efficacy†				
Reason for Concern N(%)	11 (44.0 %)	2 (18.2 %)	9 (64.3 %)	< 0.05
T-Score M(s)	42.0 (12.9)	47.3 (9.2)	**37.9 (14.2)**	0.06
NIHTB Anger‡				
Reason for Concern N(%)	12 (48.0 %)	3 (27.3 %)	9 (64.3 %)	0.15
T-Score M(s)	57.4 (11.4)	53.3 (10.2)	**60.6 (11.5)**	0.11
NIHTB Stress‡				
Reason for Concern N(%)	11 (44.0 %)	2 (18.2 %)	9 (64.3 %)	< 0.05
T-Score M(s)	57.8 (12.6)	51.2 (11.9)	**63.1 (10.8)**	< 0.05
Youth Contribution				
TRAQ50	3.80 [2.95;4.25]	3.90 [3.05;4.32]	3.55 [2.96;4.15]	0.74
AppointmentKeeping	2.43 [1.71;3.57]	3.00 [1.86;4.07]	2.29 [1.61;2.96]	0.21
TrackingHealthIssues	3.00 [1.50;4.00]	4.00 [2.38;4.00]	2.88 [1.31;3.19]	0.07
ManagingMedications	3.20 [2.20;3.80]	3.20 [2.70;4.70]	3.10 [2.05;3.75]	0.30
TalkingWithProviders	4.50 [4.00;5.00]	5.00 [4.00;5.00]	4.50 [4.00;5.00]	0.44
ManagingDailyActivities	4.00 [3.00;4.67]	4.33 [3.83;4.67]	3.33 [3.00;4.67]	0.39
Outcomes				
Anxiety (NIHTB Fear‡)				
Reason for Concern N(%)	14 (53.8 %)	4 (36.4 %)	10 (66.7 %)	0.26
T-Score M(s)	62.0 (16.4)	53.2 (13.5)	**69.0 (15.4)**	< 0.05
Depression (NIHTB Sadness‡)				
Reason for Concern N(%)	13 (52.0 %)	3 (27.3 %)	10 (71.4 %)	0.07
T-Score M(s)	56.3 (13.6)	50.2 (12.5)	**61.2 (12.9)**	**< 0.05**
Quality of Life (NIHTB Perceived Hostility‡)				
Reason for Concern N(%)	7 (28.0 %)	1 (9.09 %)	6 (42.9 %)	0.09
T-Score M(s)	51.4 (15.3)	48.0 (11.8)	54.1 (17.6)	0.31
Quality of Life (NIHTB Perceived Rejection‡)				
Reason for Concern N(%)	5 (20.0 %)	0 (0.00 %)	5 (35.7 %)	< 0.05
T-Score M(s)	51.2 (12.8)	48.4 (7.85)	53.4 (15.6)	0.30
Distress (NIHTB Loneliness‡)				
Reason for Concern N(%)	13 (52.0 %)	4 (36.4 %)	9 (64.3 %)	0.33
T-Score M(s)	57.6 (13.9)	52.3 (12.4)	**61.9 (13.9)**	0.08

† Positive NIHTB Scales, T-score below 40 is reason for concern
‡ Negative NIHTB Scales, T-score above 60 is reason for concern
N = Number, M = Mean; s = standard deviation; Mdn = Median; CI = confidence interval

3.1.2. *Theme 2: self-determination in transition process*

Self Determination is a complex concept broken out in the following subthemes: Taking active roles in healthcare, participating in decision-making, and having privacy when speaking with their providers when appropriate.

3.1.2.1. Taking active roles. Middle adolescents (~15–17 y) mentioned taking on more active roles in their care ranging from going to certain appointments (scans and lab draws) without a parent, filling out medical forms and scheduling appointments while others mention the desire but do not have a direction, "*Want to take over very soon…haven't taken any steps but looking forward to it.*" Early adolescents (~12–14 y) are happily reliant on their parents to remember and do all the necessary tasks. Many of the late adolescents (~18 y +) reported doing many of these things but did not realize these were healthcare tasks related to transition.

3.1.2.2. Time alone with clinician. Decision-making and privacy or time alone with physicians were emotionally fraught topics for middle and late adolescents. Neither of these topics were salient for early adolescents who do not quite grasp the concept of needing to take on these responsibilities. Regarding time alone, several participants discussed seeing their providers often without their parents present. Those who did not see their providers alone fell into two mindsets: 1) individuals who advocate for themselves and demand time alone and 2) individuals who have resigned themselves to never having visits alone, hoping the physicians will step in and assist with this aspect of care. This second group of participants do not feel that their parents trust in their abilities and are not comfortable voicing their desires for autonomy and privacy. One individual mentioned having depression because of these conflicts whereas another individual describes asking their physician to speak with his parents to give him "*space*."

3.1.2.3. Decision-making participation. Similarly decision-making can be inclusive with some middle adolescents permitted a power of "*veto*" and discuss alternatives when possible. On the other side are late adolescents who have the legal authority to make their own decisions yet feel like decisions are being made for them without discussion. These individuals report feeling powerless further eroding self-confidence in their own abilities. In general, individuals who suffered from mental health concerns manifesting at a later age seem to have a better collaborative relationship with their parents and experience a progressive transitioning of responsibilities. Caregivers of individuals who have had chronic conditions since birth are not advised on how to gradually transition tasks they have performed for their child's entire life and

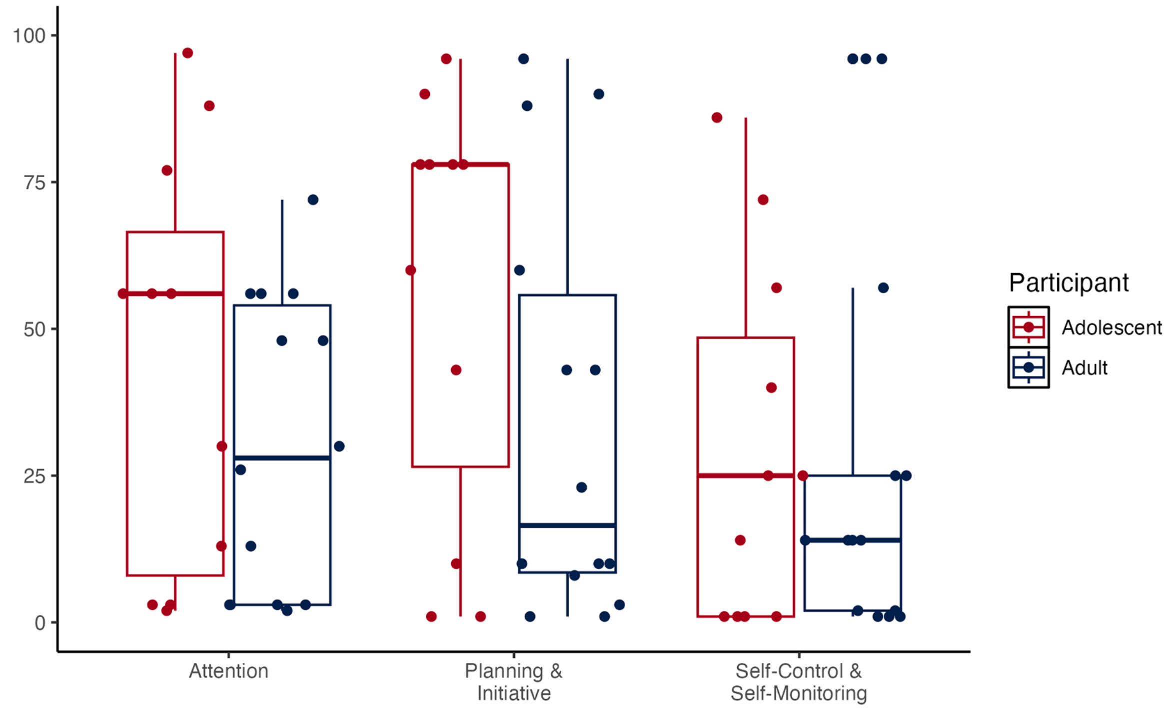

Fig. 3. Adolescent and Adult scores on AEFI representing percentile rank compared to normative peer data.

Table 3
Focus group participants.

ID	Age (Years)	Conditions	Education	TRAQ 5.0
1	12	B	7th Grade	2.3
2	12	B	7th Grade	2
3	24	V,B,ID	Finished High School	2.65
7	24	I,B	Finished High School	4.1
10	12	B	9th Grade	2.15
11	17	B	11th Grade	2.75
12	12	V,B	7th Grade	1.8
13	19	B,ID	Finished High School	2.5
18	15	I	11th Grade	3.8
23	21	B	Enrolled in college	4.2
25	12	I	7th Grade	2.5
28	20	B	Finished High School	3.26
30	15	B	10th Grade	3.05
32	16	I	10th Grade	1.95
33	23	B	Finished High School	4.7
38	28	V,I,B	Enrolled in college	1.25
40	21	I	Enrolled in college	4.4
42	16	B	11th Grade	4.2
43	20	B	Enrolled in college	3.45
34	22	B,ID	Finished High School	NA
46	20	B	Enrolled in college	4.15

*Participants 34 and 46 did not complete all the scales and are not included in quantitative data
B; Behavioral or Mental Health Disorder; I: Other Invisible Condition; V: Other Visible Condition; ID: Intellectual Disability

adolescents often need to ask for autonomy. One participant described practitioners staging events requiring parents to exit the room, thereby allowing for private conversations with the young adult.

3.1.3. *Theme 3: learning about transition*

3.1.3.1. Trial by fire. Few participants reported receiving any training regarding transition. Young adults whose parents were slowly increasing responsibilities did not connect these tasks and responsibilities as transition related. Only the individuals who were hospitalized for mental health concerns report actively being educated about self-care in the hospital. Both individuals experienced challenges related to medications that has encouraged involvement in their own healthcare. These individuals describe a trial by fire training by staff in the hospital generally preparing them for all the health management tasks that they need to perform daily to prevent exacerbations.

3.1.3.2. Room to err. Early adolescents had few ideas for how they would want to start learning about transition. Middle adolescents indicated a desire for having more time to come to terms with the changes. Both middle and late adolescents reported wanting more guided learning to provide them with opportunities for autonomous actions and decisions with a safety net allowing for mistakes or additional coaching and resources when the individual requests it.

3.1.3.3. Parent roles. Parents also need training to understand how and when to transition tasks to their child when they have been performing them since birth. Our participants believe that training for themselves and their parents would facilitate their ability to be autonomous and implement supported decision-making processes. Some participants indicate practitioners are also not treating them as adults either disclosing information said during private sessions or assuming that the individual wants their parents in the room simply because they have come to the appointment.

3.1.4. *Theme 4: concerns with transitioning*

These adolescents and young adults have had a personal relationship with their doctors for their entire lives and when told they must dissolve that relationship it can be frightening, difficult to understand and sad. Two individuals mention the trust that has been built with their doctor and the avoidance in needing to rebuild that trust again with a new provider.

4. Discussion

In general, few youth of any age in our study understood what the term “transition” entailed. Most considered it to be about a single item most commonly aging out of their parents’ insurance and changing their

Table 4
Focus group themes and quotes by age group.

	12 y - 14 y	15 y – 17 y	18 y+†
Theme:	(Mis)Understanding Transition		
		• “Hey, you have to do this. I know you don’t want to and I know you want to just keep staying in that childhood care where your mom does it for you…but you have to know that they’re not gonna always be there. You have to do it on your own.”(18) 15–1 (18) • “Me, personally, I’m, trying to learn more about how to do it for when I am older and I don’t have my parents around.”15–2-I (42)	• “I would say no, I have no like financial stability or income at all so I don’t see myself being able to pay for my appointments and medications any time soon” 24–1-C (7) • “It’s partially that I don’t know how I’d be more involved without putting money towards it, which I am unable to do.”16–3-I (46)
Theme:	Self-Determination in Transition process		
Active Roles	• “I don’t always pay attention so I have reminders plus [mom] asks questions that I don’t think to [ask].” 12–1 (1) • “Mostly my parents [manage health care] but I do some of it” 12–1-X (2)	• “I’m starting to do everything on my own… little bits of things that I do on my own so like if there’s like a test I do it on my own… but when the results are being read I always have my parents coz sometimes I don’t understand it so that I have someone to explain it to me.”15–1 (18) • “Want to take over very soon…haven’t taken any steps but looking forward to it.”15–2-S (30) • “Doing it mostly myself.”16–2-S	
Decision-Making Participation	My mom [makes the final decision]…I hate surgeries so sometimes I’ll just say no…it happens anyway… sometimes we’ll discuss things together.”12–2-K (12)	• “When there’s a decision [me and mom] communicate about it and we make a decision as a group.” 15–1 (18) • For me its like a combination of - they make the decisions and if I like agree with them…its kind of like a veto…oh that doesn’t work for me and then they’re like here’s some other options that you can do.”15–2-S (30) • If its med-wise, I kinda can’t [disagree with parent decision] because my mom needs to approve it.” 15–2-I (42)	• “[Parents make decisions] they only talk to me about it, we would have an argument, and then I would believe they want the best for me, so they still win at the end.”24–2-S (34) • “[Parents make decisions] but if it’s not fine by me, I tell the doctor about it and seek his opinion. If the doctor says something different, I’ll asked him to talk to them about it.”24–2-M (28) • “I’m mentally delayed so making some decisions is like hard so my parents are usually there but I think they make more decisions for me than I need. Like sometimes they’ll make a decision and it’s like I could have done that.” 24–1-JE (3) • “I wish I could take full control of everything. I feel I’m ready, although my level of confidence is low. I feel even now they don’t still have that confidence in me going to see the doctor alone” 24–2-S (34)
Talking with doctor alone	• “I’m comfortable with my mom talking… sometimes I talk but most of the time my mom talks. Because my mom knows a lot about it and i know some but not all” 12–1; 12–2-V-K (1,10,25)	• “I’ll ask my mom to leave the room when I talk to my psychiatrist and then me and him will like actually talk about the problem and he’ll be like well for that we can try this med and I’m like ok but how much will that cost coz I’m like afraid about money, like spending to much money on me.” 15–2-I (42) • “You have to ask your questions. Its OK to ask questions. Your doctors want to hear your opinion. But when you’re younger, when you’re five then they bring up a surgery, you have no choice. Its your parents’ decision. But now that you’re older you have a decision, even if your parents don’t like your decision, you have a decision.” 15–1 (18)	• “I refuse having my parents around when I’m with the doctor. I want to hear the doctor’s comments about my health alone. They never gave me privacy with the doctor so, I came like. hey mum, can I book my own appointment, and go see the doctor myself. They still followed me to the hospital but not inside with the doctor.” 24–2-M (28) • “I want…privacy and stuff with my appointment…when they are there when I have like therapist appointments and stuff…cause im in counseling for…depression. Sometimes there are things I want to say, but because they • are there I don’t…A lot of things happen at home…that makes my depression…worse and [my mom]…says that it doesn’t [happen], so I would like to be able to talk about it without her being there so she doesn’t contradict what I say • like all the time.”” 24- • 1-JE (3) • “For me, getting better about vocalizing that I would like to go in by myself…I’m not really good at voicing that…a lot of times I just don’t say anything so • it doesn’t happen.” 24–1-JE (3) • “I notice he [the doctor] doesn’t directly tell my mom that he wants to speak with me • privately, he will step out and then maybe someone comes to call my mom out and • maybe that’s just a way of talking to me privately.” 24–1-JS (23)
Theme:	Learning about Transition		
Trial by fire		• “I was thrown into a mental hospital and I had to learn in there everything I needed to do from the staff…They helped me understand some of the things that I would have to do when I got out. So	

(continued on next page)

Table 4 (*continued*)

	12 y - 14 y	15 y – 17 y	18 y+†
		ever since then, I have been trying to put my own amount of control into it." 15–2-I (42) • "…and then I really started to learn about what meds I need to get on because when I went to [hospital #1] I was put on 2 meds [1 for treatment and 1 for side effects management] and when I went to [hospital #2] they said …I should have been on just one…they ended up putting me on 3 so then once I was out of both…we got our own psychiatrist and now I'm only on one med."15–2-S (30)	
Coaching and having room to err		• "I've thought about starting to do the papers you get when you go into the doctor. I've thought about starting to fill my scripts on my own like with a little reminder like 'hey, you have to do it'." 15–1 (18) • "I wish the hospital…had…a little like…class about it so then like teenagers that are starting transition can understand what they have to do it and what responsibilities they're gaining and decisions and choices." 15–1 (18)	• "Having someone to help us out so I can learn to take advantage of the resources myself" 24–1-JE (3) • "Mostly me coz I know how to do it…my mom taught me how to do my appointments and talk to my doctor through the app."16–2-A (40) • "To me, even though I'm at the age where I can obviously make my own decisions, I still see that I need all the help that I can get." 16–2-S (33) • "I think if I'm given a chance to make a little mistake before someone else jumps in to help." 24–2-S (34)
Parent Roles		• "I feel like…some parents don't let their kids do it at all and some parents are like you are doing it all on your own like 'I'm not helping you at all.' So I feel like the parents need to help a little but be there "semi-" to help a kid if they missed something…to let their kid learn how to do it and teach them how to do it because if the kid doesn't know how to do it, they're not gonna know how to do it at their first [adult] appointment on their own." 15–1 (18)	• "My parents listen to the doctor, sometimes I beg the doctor to helps me talk to them for some space. A study program for my parents will help so they learn when to step back and when not to."24–2-S (34) • "Health care providers should not disclose everything we tell them to our parents." 24–1-JE (3)
Theme:	Concerns with Transitioning		
		• "I feel ready for it but…I've trusted [my current doctor] for basically my entire life, so I have to learn to trust a new doctor. That's what's nerve-wracking for me."15–1 (18)	• "I really like my [doctor] and I trust him a lot and I haven't been really motivated to find another [doctor]."24–1-C (7)

†Includes individuals who are still seeing their pediatric providers and those who have recently switched to adult providers (within the past 24 m)

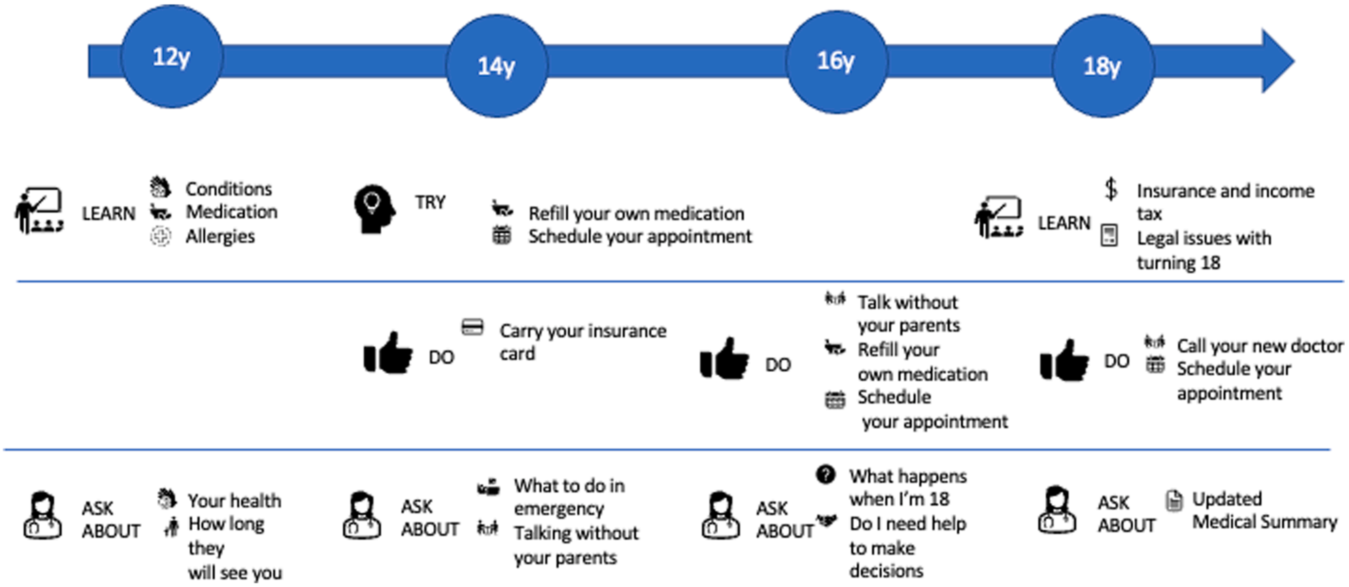

Fig. 4. Study Visual demonstrating aspects of youth transition responsibility by general developmental maturity age translated from *Got Transition® Health Care Transition Timeline for Youth and Young Adults.*

pediatric specialist to an adult specialist. A few individuals understood the holistic need for learning to manage their own care as adults due to the mortality of their parents and the need to serve in adult roles. This lack of understanding required a pivot in our focus group approach from fuzzy cognitive mapping of negative and positive elements in the transition process, to more foundational aspects of transition such as agency, self-determination and collaborative decision-making with their parents and guardians. Other studies have similarly found a global lack of healthcare transition understanding.[33]

Despite the lack of global understanding of transition, our cohort reported high scores in their perceived ability to talk to their providers. Interestingly, scores for the day-to-day management of their conditions including medication management, health monitoring, managing daily activities and appointment tracking was more variable but consistently below 3.5 out of 5.0 for the young adults. Most of the individuals who had adolescent onset psychiatric issues were taught about the need for self-management at the time of initial clinical presentation whereas the other individuals were diagnosed early in life and are aging into adolescence and adolescent roles without the same guidance or responsibility. Parents of individuals with later onset diagnosis do not have the same challenges of giving back responsibilities to their child that they have been managing for years. The majority of the research assesses transition readiness in conjunction with successful youth-to-adult healthcare transition outcomes. However, recent calls for action have demonstrated the need to have flexible approaches to increasing their autonomy and independence prior to transition.[8,34]

Loss to follow-up is significant concern for individuals living with a chronic pediatric onset disease. A recent scoping review on chronic illness demonstrated lost to follow-up ranging 8–89 % and patient reported factors are common across conditions minimizing the need for care, unaware of the need for long-term follow-up care, and inability to navigate adult health care systems.[35] For some conditions like congenital heart disease[36] and spina bifida[37] the risk and implications of acquired comorbidities can be severe.

A systematic review of articles discussing youth healthcare transition found perceived self-efficacy to be consistently associated with transition readiness.[38] Ineffective transition can lead to lower academic and employment achievement in populations.[39,40] We found a significantly higher proportion of our older participants at or below the cutoff for concern in 64 % of our older adults and the overall mean for the group was below the cutoff (T-Score M 37.9, SD 14.2). in 7 of 9 scales indicating a high risk for mental health and emotional well-being issues. In our sample, older individuals significantly differed from their younger counterparts in either the proportion of the group reporting a reason for concern score or the overall mean score of the group falling within the reason for concern range in eight of nine NIHTB scales.

This coupled with the general lack of knowledge about the concept of transition overall and the lack of difference between younger and older group transition readiness perspective demonstrate a potentially disturbing pattern of decline in life outlook in late teens and early adulthood, possibly exacerbating an inability to self-manage and behave in a self-directed manner.

Efforts need to be made to increase knowledge and maintain the positive perceptions of youth associated with their self-efficacy regarding managing their health, developing resilience and ownership of their health management. Research into adolescent engagement in health care using technology is not robust despite the natural affinity for technology in children in adolescents.[41] There are opportunities for personalized monitoring and preventative care using artificial intelligence such as interactive narratives (chatbots), gamification for intervention compliance and alternative platforms for patient provider communications.[42–45] However, authors emphasized the need for participatory inclusion of adolescents in development of technology interventions.[43,46]

4.1. Strengths and limitations

The strengths of our study are the use of mixed methods to assess transition readiness in youth which includes data across the Expanded SMART model as well as youth perceptions on their transition training, autonomy and self-efficacy in managing their chronic illness.[13] The limitations are those inherent in all pilot studies which is the small sample size which will be increased in future iterations. The fact that none of the youth understood the concept of transition required a pivot in our research, which originally intended to map the experiences of youth transition processes to the expectations of providers. Instead, we focused on generating an understanding of how they felt about the concepts of guided decision-making and the process of disagreeing with their parents and physicians.

5. Conclusions

A directed attempt to create self-efficacy in transition activities, specifically health management, educating individuals with special health care needs to understand the meaning of transition and promoting a more positive perception of transition is needed. It is evident that our young adults are negatively affected by their inability to behave and be treated as adults and decision-making has become and all or nothing proposition rather than allowing for supported decision-making and/or power of attorney before instituting legal guardianship. Next steps involve employing adolescents in young adults to develop a better pathway towards building a better understanding of transition and help youth prioritize taking on the responsibility of managing and advocating for their own health.

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Abbreviations

(NIHTB), National Institutes of Health Toolbox; (SMART), Social-Ecological Model of Adolescents and Young Adult Readiness for Transition; (TRAQ), Transition Readiness Assessment Questionnaire; (AEFI), Amsterdam Executive Function Index; (YDMC), Youth Decision-Making Competence

Ethical Statement

Authors will follow ethical guidelines stated in Elsevier's Publishing Ethics Policy.

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Wahl Richard: Writing – review & editing, Conceptualization. **Shifren Rena:** Writing – review & editing, Methodology, Investigation. **Andrews Jennifer G.:** Writing – original draft, Visualization, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. **Klewer Scott E.:** Writing – review & editing, Conceptualization. **Parent-Johnson Wendy:** Writing – review & editing, Conceptualization.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests

Jennifer Andrews reports financial support was provided by The University of Arizona. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data will be made available on request.

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