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Dynamic assessment of a transition process for patients with diabetes

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ABSTRACT

Introduction: Adolescence can be defined as the period during which all individuals move from childhood to adulthood, including in the healthcare system, creating a need for a healthcare transition process. Children's of Alabama provides four transition education sessions during clinic visits for adolescents with type 1 diabetes (T1D). We aimed to assess baseline patient data and patient perspectives of our current transition education process to guide our efforts to improve this process.

Methods: We used a mixed methods design comprised of a quantitative analysis of baseline data in our adolescents with T1D and qualitative analysis of provide and patient perspectives. We queried the electronic medical record to obtain baseline characteristics of adolescent adolescents with T1D seen at our center from January 2022 to May 2022 and sought input via anonymous surveys of adult and pediatric endocrinology attendings, fellows, and nurse practitioners at our institution and of adolescents with T1D who had completed the final education session via an electronic secure database.

Results: Electronic Medical review of adolescents with T1D transitioning to adult care at our center revealed most of our adolescents with T1D had a gap in care of four months or greater between last pediatric visit and first adult visit. Pediatric provider surveys emphasized barriers for adolescents with T1D with appointment scheduling and challenges navigating the adult health care system. Adult surveys emphasized lack of communication with the adult health care team. Adolescents with T1D overall reported transition education prepared them well for adult care, but only 35.3 % had identified an adult provider after completing transition education.

Conclusions: Our findings outline additional areas for improvement in our transition process for adolescents with T1D. Based on feedback from the pediatric team, we are working to initiate transition education by age 16, standardize document discussions around transition, document date of planned transition, and document planned accepting adult provider. We are working to streamline record transfer based on feedback from adult providers. Based on patient feedback and our documented gaps in care, we are working to place referrals for adult care to minimize gaps in diabetes care.

1. Introduction

Adolescence can be defined as the period during which all individuals transition from childhood to adulthood. For children with chronic diseases, adolescence is also the period during which their health care shifts from a pediatric to an adult model. For those with type 1 diabetes (T1D), the complex interplay between ongoing social-emotional development, structural barriers to healthcare access, and disease natural history increase the risk of acute complications of diabetes, such as diabetic ketoacidosis (DKA) and severe hyperglycemia, as well as worsening of glycemic control and development of chronic complications of diabetes.[1,2] Due to competing life demands, adolescents with T1D commonly report gaps of care of six months or greater during the transition from adult to pediatric care which can increase the risk of these adverse outcomes. [3,4]

Previous work evaluating transitions of care for youth with chronic medical conditions have led to the development of transition questionnaires.[5] However, a dearth of evidence of best practice for transition timing and education exists.[4] Many institutions, including our own, have implemented transition education curricula for adolescents with T1D with an aim of improving adolescent and family preparedness for the transition to an adult care model. This preparation is recommended by

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the International Society for Pediatric and Adolescent Diabetes (ISPAD) consensus guidelines which recommend starting at early puberty[6,7,8] Prior studies have shown that optimal transition occurs with a strategic planned process as this can improve the adolescent and young adult confidence in taking charge of their own health care.[9,10] Given the increased risk of acute DKA and development of chronic microvascular complications associated with adolescence, an ideal transition process would also help improve glycemic control and reduce the risk of acute complications for adolescents with T1D, but there are currently no clear best practices for transition to address these risks.[11] Previous work has not shown a clear association between components of transition of care curricula and outcomes, however use of telehealth and virtual group appointments have been shown to decrease diabetes distress, improve quality of life, and improve communication between adolescents and healthcare professionals.[12] There is also emerging evidence that the use of digital technologies lead to improvements in resilience capacities, a finding that could be particularly pertinent for adolescents in the period of transition which for youth with T1D extends to use of continuous glucose monitor (CGM) and insulin pumps during the time of transition.[13]

1.1. Local context

Children's of Alabama (COA) has an existing transition education curriculum for youth with T1D, but the effect on the experience of adolescents with T1D and their providers with transitions of care is unknown.

Youth with all forms of diabetes receive diabetes care in the COA diabetes clinic. At the time of our study, there was no existing clinic or hospital policy limiting care at COA after a designated age. Our current transition education protocol consists of a series of classes taught by diabetes educators during routine diabetes visits (See Table 1). A certified diabetes educator meets individually with our adolescents with T1D and to provide education on the topics summarized below. Class length is tailored to the individual adolescents with T1D but typically lasts 30–60 minutes. Transition education initiation is a shared decision between providers, adolescents with T1D, and educators and may start as early as 14 years. Our goal is for adolescents with T1D to have completed class 1 prior to age 16 and is a prerequisite for completing state mandated driving paperwork.

Table 1

Current transition education curriculum at Children's of Alabama.

	Target Age	Topics Covered	Additional Resources Provided
Class 1	15–16	Discussion of A1C and goals for glycemic control, define transition, driving and alcohol use with diabetes	ADA hand out on alcohol, summary of Alabama laws and requirements for driving with insulin use, hand out on complications
Class 2	16–18	Review resources and legal protections for people with diabetes in the workplace, discuss insurance options with social worker, list diabetes related medications and supplies	List of adult Endocrinologists and diabetes providers broken down by city/region, hand out on diabetes and carb counting apps, list of transition websites for adolescents.
Class 3	16–18	Review resources on mental health care, discuss accommodations for diabetes in a higher education setting, review sick day guidelines	Summary sheet of insurance options, Alabama Department of Rehabilitation Services handout, College Diabetes Network handout
Class 4	By age 19 or high school graduation	Nutrition consultation, social work consultation, review of hypoglycemia prevention and treatment	Additional copy of list of adult Endocrinologists and diabetes providers, Lily My Diabetes Emergency plan handout, handout of hypoglycemia treatment

1.2. Project aims

This study aims to use quality improvement (QI) tools to assess our current transition process and engage key stakeholders to better understand the effectiveness of our current transition protocol, identify barriers to transition for adolescents with T1D, and guide our future QI work for adolescents with T1D transitioning from pediatric to adult care.

Our primary objective was to assess baseline percentage of adolescents with T1D over age 19 who are seen for T1D and determine the average length of time between the last pediatric appointment and first adult appointment for adolescents with T1D treated at our center. Our secondary aim was to receive stakeholder input about the existing process. We aimed to engage all stakeholders including adolescents with T1D, adult Endocrinologists and fellows, and pediatric Endocrinologists, fellows, and nurse practitioners to best identify barriers and facilitators in the current process of transition and provide insights into areas for improvement. The overall aim of this work is to obtain baseline data and stakeholder perspectives of the existing transition process for youth with T1D at our center.

2. Methods

2.1. Background

This protocol was reviewed by the UAB IRB and not-human subjects research classification was requested as the primary objective was to review an existing process. Anonymous surveys were the only direct contact. Adolescents with T1D were informed that participation in the survey was voluntary, anonymous, and would not impact their care or relationships at Children's of Alabama. Protocol number: IRB-300009395 was reviewed by the UAB IRB and deemed not human subjects research. No consent was required.

We queried the electronic medical record to evaluate the characteristics of adolescents age 14 + years seen in the clinic for T1D from January 2022 to May 2022 and collected age, glycosylated hemoglobin (A1C), insurance payor, race, and sex. In January 2022, readily available data regarding completion of transition education classes was available in our electronic health record, making this an ideal time to start evaluating the completion of transition education classes. Inclusion criteria included adolescents with T1D of any duration who were age 14 years + at the time of the clinic visit as indicated by the ICD-10 code E10.65 and English-speaking ability due to limitations in our transition education materials. Due to limitations in our diagnosis codes, we were not able to distinguish between insulin use and non-use for adolescents with type 2 diabetes, however, we include youth with type 2 diabetes using insulin in our transition curriculum and solicited their feedback via survey regarding their experience with our transition education. Exclusion criteria included diabetes of other types including type 2 diabetes with exception noted above, medication-induced diabetes, diabetes due to underlying illness such as chronic pancreatitis or cystic fibrosis. These adolescents were excluded from the study as the curriculum is altered and shortened for these adolescents and to adequately assess all aspects of the curriculum, these adolescents were excluded from inclusion.

2.2. Planned analysis

2.2.1. Quantitative analysis

Demographic variables collected included sex, age, insurance, race, ethnicity, and language. Categories of insurance were publicly insured (Medicaid, Medicare) or "other". Percentage of adolescents with T1D who have started transition education and completed the final class were calculated. Demographics as well as starting/completing rates of transition education for adolescents with T1D age 19 + years old were compared to adolescents aged 14–18. For adolescents with T1D 18 years and over, the University of Alabama at Birmingham medical record was also queried to assess if an adult appointment had been attended or if any hospital admissions outside of COA within our institution had occurred. The length of time from last pediatric appointment at COA to first adult appointment for adolescents with T1D transitioning care to UAB was calculated (Table 1).

2.2.2. *Qualitative analysis*

To assess the perspectives on the current transition curriculum from adolescents with T1D and families, educators gave surveys to adolescents with T1D and parents at the conclusion of the final transition education class. As class materials were available only in English at the time of data collection, only adolescents with T1D able to read English completed the survey. The survey addressed five questions: if the adolescent had identified an adult provider, if the adolescent felt the transition program prepared them for transition, what the favorite part of transition education was, what the least favorite part of transition education was, and what recommendations adolescents with T1D had to the existing process. We also surveyed physicians and nurse practitioners anonymously via an electronic secure database to solicit feedback about the existing transition process. Survey questions included: age at which transition discussions should begin with adolescents with T1D, age at which adolescents with T1D should transition, age at which most adolescents with T1D currently transition, barriers to successful transition, and adequacy of communication with the adult care team at the time of transition.

To obtain input from adult care stakeholders we anonymously surveyed adult Endocrinology attending physicians and fellow physicians at UAB Kirklin Clinic. Survey questions addressed length of time since last pediatric visit, if a medical summary was received prior to first appointment for adolescents with T1D transitioning from COA diabetes clinic, adequacy of communication with pediatric care team, and familiarity with the American Diabetes Association position statement on transition of care. Thematic analysis as described by Braun and Clarke was used to analyze survey results. Two study team members then independently reviewed the free text answers to survey questions and grouped them into main themes. The survey data was coded together by two study team members with qualitative research experience. The use of inductive thematic analysis allowed for generation of codes from the data itself while the deductive analysis will allow for a structured analysis of the data, thus creating a conceptual framework. The team members then determined major themes and subthemes in the data. In brief, the steps included becoming familiar with the data, generation of initial codes, searching for themes, reviewing themes, and a final analysis. The integration took place after both team members analyzed separately. The first step will be sorting the interview findings and document analysis findings. In the second step, the two files were compared with respect to the meaning and interpretation of themes and convergence coding schemes were applied between the two sets of results. The next step is looking for agreement in both meaning of themes. Step 3 included convergence assessment to compare findings between the two data sets. Step 4 included completeness comparison where they highlighted both similar and unique contributions to the research questions. This work is utilized to look at core themes. Once the data was coded into several domains, it was then summarized in tables. A sentence summarizing the key themes that emerged is presented following each table(Braun and Clarke 2006).[14]

3. Results

3.1. *Quantitative analysis*

During the January to May 2022 period, 852 unique adolescents age 14 years + with T1D attended 1221 clinic visits. During that period, the average age at the time of the visit was 16.8 ± 1.8 years old with 129 (10.6 %) adolescents aged 19 + . There was no gender or race/ethnicity difference between younger and older adolescents. Adolescents aged 19 + years had higher rates of non-English language use (5.4 % vs 2.3 %, $p = 0.035$) than their younger counterparts (14–18 years). Overall, 30.4 % of adolescents had started transition education, and transition education initiation. Rates of public insurance were lower in our 19 years and older adolescents with T1D (22.5 % vs 39.4 %, $p < 0.001$). 86 adolescents with T1D were identified as being 18 or older and referred to UAB Kirklin clinic for adult care. For this group of adolescents with T1D, the majority (69.41 %, $n = 86$) of adolescents with T1D had a gap in care of four months or greater between the last COA appointment and first adult appointment (Table 1). Four adolescents with T1D in this group also had their first adult appointment with maternal fetal medicine rather than Endocrinology due to pregnancy that occurred prior to establishing care with adult Endocrinology Table 2.

3.2. *Qualitative analysis*

The survey quantitative data are presented followed by key themes that emerged from the survey questions.

3.2.1. *Adolescent with T1D Input*

34 adolescents completed transition education during the study period and submitted a survey. The majority of adolescents with T1D, $n = 33$ (97.1 %), felt the existing process prepared them for transition, however only a minority, 12 (35.3 %) had identified an adult provider. Tables 3 and 4 Of the 22 adolescents with T1D who reported not having identified an adult provider, the majority ($n = 15$, 68.2 %) reported they had not chosen one yet or hadn't investigated finding one yet. Only 1 of the 22 (4.5 %) indicated they were actively looking for an adult provider. Fifteen adolescents with T1D responded to the question about the least favorite part of transition education.

Key themes regarding the most challenging parts of transition included reluctance to leave their pediatric Endocrinologist and completion of paperwork.

More adolescents with T1D ($n = 28$) responded to the question about their favorite part of transition education. Common themes in favorite parts of transition included learning more about diabetes management and working with the staff (diabetes educators, physicians).

When adolescents with T1D were asked to provide suggestions for changing the existing education process and materials, one requested stapled papers rather than folders, one requested more pictures and lists with information, and the remainder had no changes suggested.

3.2.2. *Pediatric provider input*

Fourteen pediatric providers including fellows, attending physicians, and nurse practitioners completed the survey.Tables 5, 6, 7, 8 and 9 The majority of pediatric providers felt that age 15 or older was appropriate to begin discussing transition. Age 18 or 19 were identified as appropriate for transition to adult care, but about half of respondents felt that age 20 was when adolescents with T1D transition in our clinic. Difficulty with navigating the healthcare system and difficulty with identifying an adult provider were frequently identified as barriers for adolescents with T1D in our clinic to transition. Most pediatric respondents also felt that

Table 2
Length of time between last pediatric and first adult appointment for adolescentstransitioned from CoA to UAB between 01/01/2019–12/31/2021.

Months between last CoA appt and first UAB appt	Number of Adolescents	Percent
< 4 mos	26	30.59
4–7 mos	17	20.00
7–12.5 mos	23	27.06
> 12.5 mos	19	22.35
Total	82	100

Table 3
Adolescent with T1D questionnaire: Question 1: What was your least favorite part of transition? n = 15.

Answer	Frequency of response	Percent
Knowing I have to leave my doctor	3	20.0
Paperwork, completing TRAQ	3	20.0
Knowing change is coming	2	13.3
Learning about money/cost of diabetes	2	13.3
Other	5	33.3
Total	15	100

Table 4
Adolescent with T1D questionnaire: Question 2: What was your favorite part of transition?.

Answer	Frequency of response	Percent
Learning more about diabetes management	8	28.6
Working with the staff	3	10.7
Meeting other medical professions (nutrition, social work, educator)	2	7.1
Talking with my doctor about my options, getting their input	2	7.1
Everything	2	7.1
Other	11	39.3
Total	28	100

Table 5
Pediatric provider survey question 1: What age do you feel we should start discussing Transition.

Age	Frequency of response	Percent
12	2	16.7
13	1	8.3
14	1	8.3
15	4	33.3
16	3	25
Depends on the situation	1	8.3
Total	12	100

Table 6
Pediatric provider survey question 2: What age do you think it would be appropriate to transition most adolescents with T1D?.

Age	Frequency of response	Percent
18	6	50
19	6	50
Total	12	100

Table 7
Pediatric provider survey question 3: What age do you think you transition most of your adolescents with T1D?.

Age	Frequency of response	Percent
18	3	23.0
19	4	30.8
20	4	30.8
16	1	7.7
For bone, 17	1	7.7
Total	13	100

communication could be improved with the adult care team at the time of transition.

A majority of pediatric providers felt that age 15 or 16 is an appropriate time to begin transition education for adolescents with T1D.

Pediatric providers were evenly split between 18 and 19 when asked what age it is appropriate to transition to adult care.

Table 8
Pediatric provider survey question 4: What barriers do you note make it difficult for your adolescents with T1D to successfully transition?.

Theme	Frequency of response	Percent
Lack of motivation to find new provider	3	33.3
Lack of knowledge	3	33.3
Continuing with other pediatric care	1	11.1
Difficulty with navigation of the transition process	2	22.2
Total	9	100

Table 9
Pediatric provider survey question 5: Do you think that communication with the adult endocrinology team is adequate for adolescents transitioning to adult care?.

Response	Frequency of response	Percent
Yes	4	30.8
No	9	69.2
Total	13	100

However, when asked at which age they thought transition typically occurred for adolescents with T1D in our clinic, 30.8 % identified age 20 as the age at which they typically transition their adolescents with T1D to adult care.

Lack of motivation to find a new adult provider and lack of knowledge of the adult healthcare system in adolescents with T1D were the primary barriers identified by pediatric providers in transitioning their adolescents with T1D to adult Endocrinology.

Most pediatric providers felt that communication with adult providers was not adequate for adolescents with T1D for whom they were transitioning care to adult Endocrinology.

3.2.3. *Adult provider input*

Eight adult providers including fellows and attending physicians completed the survey. The majority of adult providers felt that the time since last diabetes visit for adolescents with T1D transitioning to their practice was more than 6 months at the time of transition Tables 10, 11, 12 and 13.

Less than half of respondents reported receiving a medical summary from the pediatric team prior to seeing an adolescent with diabetes transitioning from pediatric care.

Most respondents also felt that communication with the pediatric care team was “probably not” or “definitely not” adequate

Only 25 % (2/8) of adult providers who responded were familiar with the American Diabetes Association position statement on transition of care.

4. Discussion

Our results highlight several areas for improvement in our transition process for adolescents with T1D. Baseline data for adolescents with T1D transitioning from our clinic to UAB for adult care revealed a gap in care for routine diabetes appointments occurring at the time of transition. We also found four adolescents with T1D at our center had their first adult

Table 10
Adult provider survey question 1: For young adults new to your care, how long is the gap from the last pediatric visit to the first adult visit?.

Answer	Frequency of response	Percent
< 3 months	0	0
3–6 months	1	12.5
> 6 months	7	87.5
Total	8	100

Table 11

Adult provider survey question 2: How often do you receive a medical summary prior to seeing an adolescent with diabetes transitioning from pediatric care?.

Answer	Frequency of response	Percent
Less than half the time	4	50
About half the time	1	12.5
More than half the time	3	37.5
Total	8	100

Table 12

Adult provider survey question 3: Do you feel that communication with pediatric providers for adolescents transitioning from pediatric to adult care is adequate?.

Answer	Frequency of response	Percent
Definitely not	2	25
Probably not	3	37.5
Might or might not	0	0
Probably yes	2	25
Definitely yes	1	12.5
Total	8	100

Table 13

Adult provider survey question 4: Are you familiar with the American Diabetes Associations position statement?.

Answer	Frequency of response	Percent
Yes	2	25
No	6	75
Total	8	100

Table 12—Adult provider survey question 4: Are you familiar with the American Diabetes Associations position statement?

appointment with maternal fetal medicine, highlighting a need to discuss preconception planning and pregnancy risks as part of our counseling on complications and long term health during the transition process. The fact that a majority of adolescents with T1D (69 %) had gaps in care of more than four months during the transition process within our own institution suggested that referrals needed to be sent in advance of the final visit.

Responses from adult Endocrinologists at UAB reaffirmed that most adolescents with T1D presenting to establish adult care had a significant gap of > 6 months since last pediatric diabetes appointment and this perception was validated in our data analysis. These responses also highlighted a need for re-evaluating our transfer of records process within our institution as UAB and CoA utilize different EMR systems. Given that both adult and pediatric providers within a single institution identified communication as an area for improvement, it seems unlikely that adult providers working outside our institution are receiving adequate communication from our pediatric clinic for adolescents with T1D transitioning into their practice. A designated summary document could assist in timely and targeted communication for adult providers both within and outside our institution. Most adult providers were unfamiliar with the ADA guidelines on transition which suggests an opportunity within our institution to collaborate as we work to improve our transition education.

Responses from adolescents with T1D highlighted barriers with making an appointment with an adult provider and navigating the healthcare system. If funding could be obtained, a transition coordinator or designated staff member as suggested in the ISPAD guidelines is one potential avenue to help reduce the barrier and ensure timely appointments are made prior to discharge from pediatric care. [6] A previous single center study showed that a transition coordinator played an essential role in facilitating successful transition of care to the adult clinic.[13] In a meta study of four randomized control studies looking at interventions including workshops as well as web-based or short message service-delivered information showed an improvement in higher self-efficacy score and confidence in managing their own health.[15] In our study, responses from adolescents with T1D identified some reluctance to change providers and responses from both pediatric and adult Endocrinologists identified inadequate communication regarding adolescents transitioning to adult care. Adolescents with T1D also identified concerns about insurance and cost of diabetes and in our state, where Medicaid coverage ends at 19, highlights a need for ongoing advocacy work to ensure older adolescents have access to standard of care insulin and technology for their diabetes management.

We have implemented several changes in our transition process to address these areas that need improvement.

1. Transition contract with planned date of discharge from pediatric practice to be completed at the beginning of transition education.
2. Creation of a transition summary document with relevant labs, DKA history, and technology use to be sent to adult providers at the time of discharge from our practice and to be provided to adolescents with T1D at the time of transition.
3. Standardized documentation in our pediatric clinic for adolescents with T1D 16 and older that includes prompts for planned transition date and planned adult provider to help providers and families proactively identify an adult provider prior to the date of transition.

All of these interventions were identified through mixed methods analysis of baseline clinic data for youth with T1D and adolescent, pediatric provider, and adult provider input all from within a single institution. A QI lens allows for dynamic modifications to our process to meet the goals of providing adolescents with T1D with transition education that results in successful transition into adult diabetes care. We are continuing to work to assess further adjustments needed to our process with a plan do study act (PDSA) cycle.

There were several limitations to our study. There are many stakeholders in this process and a weakness of our analysis is that we did not have a way to seek input from all adult providers our adolescents with T1D transition to outside of UAB/COA. Future surveys could also be improved by standardizing questions asked of providers to aid in comparison. We utilized different questions in an attempt to better solicit free text feedback, but this limited our ability to directly compare the adult and pediatric provider results. A future study with interviews of both providers and adolescents who have completed transition would likely allow us to better tease out some of the details in the areas for improvement and barriers identified by our stakeholders.

Although this work focused on adolescents with T1D with T1D, many of our adolescents with T1D with type 2 diabetes or other Endocrine conditions transition to adult primary care providers who might identify different areas for improvement in our transition process, and adolescents with T1D with type 2 diabetes have previously been shown to be less likely to have an established health care provider for their diabetes and be more likely to have public insurance which may result in loss of insurance in many states, including ours, around the age of transition.[2] Our surveys of adolescents with T1D were also limited to adolescents with T1D who read and write English which could miss key needs in our non-English speaking population.

Our analysis of a single center experience was a low-cost intervention that allowed us to obtain key information to guide modifications to our existing transition process. We do not yet know if these changes will meaningfully alter the gaps in care and communication experienced by our adolescents with T1D and providers around the time of transition. Prior studies that have utilized a facilitator to help adolescents navigate a structured transition of care protocol have shown that this model to have improved satisfaction rates of adolescents.[16,17] The use of technology and peer supports have also been shown to reduce diabetes distress and improve communication between adolescents and their healthcare providers which could significantly impact adolescents who may be starting to take over primary communication with their health care team from their parents.[12,13] Use of technology to facilitate transition care could improve adolescents access and help share existing educational curricula amongst institutions.Utilizing a transition of care clinic with a multidisciplinary clinic comprised of adult and pediatric team members has been shown to be effective in improving glycemic control and decreasing loss to follow-up, however this may be difficult to implement on a large scale.[18] While our work focuses on adolescents with diabetes, use of stakeholder surveys to dynamically modify our transition education process diabetes could be adapted for many other populations. We will continue to work to assess both outcomes of our transition process and identify new areas for improvement to work to reduce diabetes related risks in young adults transitioning from pediatric to adult care.

Financial statement

We received no institutional or outside funding for this work.

Ethical statement

This project was reviewed the Institutional Review Board for the University of Alabama at Birmingham. It was determined to be exempt from informed consent as it was approved under quality improvement work.

CRediT authorship contribution statement

Schmitt Jessica: Writing – review & editing, Methodology, Investigation. **Allan Sarah:** Writing – original draft, Methodology, Investigation, Conceptualization. **Foster Christy:** Writing – review & editing, Methodology, Formal analysis, Conceptualization.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Sarah Allan reports a relationship with The University of Alabama at Birmingham that includes: employment. 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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