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Integrating transition readiness assessment into clinical practice: Adaptation of the UNC TRXANSITION index into the cerner electronic medical record

Wendy N. Gray, PhD^{*}, Lauren Partain, LCSW, Erin Benekos, NP, Kenneth Grant, MD, Michelle Kennedy, LCSW, Parasto Dorriz, MPH, Anne Carpinelli, MD, Karina Chavez, MSW, Christine Yun, NP, Lilibeth Torno, MD, Daniel Shrey, MD, Mark Daniels, MD, Michael Weiss, DO

Children's Health of Orange County, Orange, CA, USA

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ABSTRACT

Purpose: To describe the process of developing, and evaluating the feasibility and acceptability of, an EMR-based transition readiness assessment.

Design and methods: A Cerner-based version of the UNC TR_xANSITION Index was implemented across four pediatric subspecialty clinics: epilepsy, inflammatory bowel disease; type 1 diabetes, oncology survivorship. The feasibility was assessed by each's clinic's ability to meet form completion goals and their assessment rate. Acceptability was assessed via family refusal rate, a staff-completed feedback questionnaire, and whether the form was adopted into routine clinical care after completion of the pilot study.

Results: All clinics met form completion goals ($N = 10/\text{clinic}$). The assessment rate ranged from 66 to 100% across clinics. No families refused completion of the form. Most staff (70%) reported completing the form in <10 min. Staff reported on challenges experienced and provided recommendations to streamline administration and enhance clinical care. All staff reported the form helped them identify knowledge gaps in their patients. Two clinics continued using the form following completion of the pilot study.

Conclusions: Implementation was most feasible in clinics that were well-staffed and had lengthier patient visits, however, time and staff resources were the biggest challenges to implementation across clinics. Based on staff feedback to improve efficiency and developmentally-tailor assessment, the form will be divided into Beginner Skills and Advanced Skills.

Practical implications: Integrating transition readiness assessment into the EMR has the potential to improve clinical care by facilitating staff's ability to efficiently identify knowledge gaps in their transition-aged patients and intervene.

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Available Knowledge

Transition to adult care is a pressing clinical issue affecting the lives of patients and parents and the clinical operations of both the pediatric and adult health care systems. When poorly managed, transition to adult care is associated with poor health outcomes, including higher rates of treatment non-adherence, drop out of medical care, increased utilization of emergency care, worsening disease state, increased need for more intensive medical treatment (e.g., surgical procedures, hospitalization), and in some cases, death (Annunziato et al., 2007;

Bowen et al., 2010; Pai & Ostendorf, 2011; Paine et al., 2014; Quinn et al., 2010). Fortunately, evidence shows that many of these adverse outcomes can be reduced, if not prevented, by having structured transition program in place (Gabriel et al., 2017; Schmidt et al., 2020).

Rationale

In late 2019, our institution embarked on an ambitious mission to create a system-wide transition program. A steering committee, composed of parents of youth with chronic conditions, providers from pediatric primary and subspecialty care, nursing, psychology, social work, care management, informatics, and quality improvement, was formed to spearhead these efforts. The committee's goal was to create a disease-agnostic transition program so that all patients, regardless of

^{*} Corresponding author at: Children's Health of Orange County, 1120 W. La Veta Ave. Ste 470, Orange, CA 92886, USA.

E-mail address: wendy.gray@choc.org (W.N. Gray).

their diagnosis/diagnoses, would transition to adult care with a foundational set of competencies required for lifelong independent disease management (Benekos et al., 2020).

The steering committee adopted Got Transition's Six Core Elements (hereafter referred to as the "Core Elements") framework to guide their multi-year program development efforts. According to Got Transition's website, "Got Transition's Six Core Elements of Health Care Transition™ 3.0 is the widely adopted approach called for in the 2018 Clinical Report on Health Care Transition from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians" (<https://www.gottransition.org/six-core-elements/>). As its name indicates, the Core Elements identify the basic components to guide a structured transition, which includes: 1) development of a transition policy/guide, 2) creating a registry to monitor and track patient process, 3) assessment of transition readiness on an annual basis, 4) development of a health care transition plan and medical summary, 5) transfer to adult healthcare, 6) transfer completion and attainment of patient/family feedback on the transition process. Since adopting this framework, the steering committee has implemented the Core Elements in numerical order. Following adoption of a hospital-wide transition policy (Core Element #1) and creation of a transition registry (Core Element #2), the committee focused its attention on Core Element #3: transition readiness assessment.

Several organizations, including Got Transition, recommend assessing transition readiness as part of transition planning (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group, 2011; White et al., 2018). The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians suggest "regardless of the tool chosen, it should contain specific minimum components that provide an accurate, point-in-time assessment of the individual patient's ability to transition successfully" (American Academy of Pediatrics et al., 2011). Arriving at an accurate point-in-time assessment requires an evaluation of a patient's true abilities and knowledge. This includes an assessment of a patient's knowledge (i.e., knowledge of condition, treatment, and medical history) but also their broader transition skills, such as their understanding of health care system navigation and their self-management skills. This cannot be accomplished via self-reported measures, which overestimate one's true skills and abilities due to social desirability (Ferris et al., 2012). Thus, to arrive at an accurate point-in-time assessment, a formal evaluation is needed.

Once a tool is selected, it must be integrated into the clinical care workflow. Lack of staff, time, and limited financial support for transition activities remain major barriers to creating and maintaining a transition program (Gray et al., 2018). Electronic medical record (EMR)-based transition readiness assessment reduces burden by enabling automatic scoring, interpretation, and documentation of results. Using a validated measure and documenting results in the EMR may also facilitate reimbursement from insurance providers. This is especially important as transition services have historically not been reimbursed (Philbin et al., 2017) and financing such efforts remains a major barrier to the effectiveness and sustainability of transition programs (Bryant et al., 2011; Gray & Maddux, 2016; Paine et al., 2014). Embedding transition data directly into the medical record also underscores the role of transition readiness within standard patient care and can enhance clinician engagement in, and implementation of, transition services (Wu et al., 2021). Finally, EMR integration enhances accessibility of these data across a broad scope of pediatric health care disciplines.

Despite the potential benefits of EMR-based transition readiness assessment, few have reported on its use (Bindiganavle & Manion, 2022; Huang et al., 2020; Little et al., 2017). The existing literature is limited to single-disease populations, limited data on feasibility and acceptability of EMR-based assessment, and redundancy in workflow and increased staff burden (e.g., utilizing pen-and-paper measures that are later entered into the EMR by staff).

Specific Aims

Our paper moves the literature forward by being the first to translate a clinician-based assessment (i.e., not patient report) of transition readiness into the EMR. Our assessment directly occurs within the EMR and is tested across several patient populations, including those with IDD. We present data examining the feasibility and acceptability of our work, discuss modifications when assessing transition readiness in patients with intellectual and developmental disabilities (IDD), and offer recommendations for others who seek to integrate EMR-based transition readiness assessment into clinical care based on our lessons learned.

In this project, we had several exploratory aims: 1) Determine if clinics can administer at least 10 EMR-based transition readiness assessments within a 4-month period, 2) Evaluate effectiveness at integrating transition readiness assessment into the clinic workflow, 3) Determine family refusal rates for transition readiness assessment, 4) Obtain feedback from staff who utilized our tool, 5) Determine if clinics were willing and able to adopt transition readiness assessment as part of routine care, and 6) Explore how transition readiness can be assessed in patients with co-occurring IDD.

Methods

Context

The current section outlines the process of creating, evaluating, and modifying our EMR-integrated transition readiness assessment.

Measure selection & EMR Integration

Our steering committee sought a validated transition readiness measure that: 1) serves as an accurate point-in-time assessment of a patient's true knowledge and abilities, 2) has a short administration time so as not to significantly impact clinic workflow, 3) allows for the assessment of patient-specific information (i.e., current medication regimen), 4) assesses broader transition skills relevant for all patients, 5) allows for parental report in the event of limited youth capacity, and 6) is disease-agnostic. The benefits of a disease-agnostic tool are multifold. First, transition tools do not exist for every disease population. Using a disease-agnostic tool enables assessment when working with all populations (Zhang et al., 2014). Second, a disease-agnostic measure allows for the use of a single tool. This is especially helpful when working with diverse populations seen in primary care (Schwartz et al., 2014). Use of a single tool also allows for the collection of larger sample sizes for research purposes and, due to the robustness of the measure across disease populations and settings, it allows for the comparison of results on a broader level (Zhang et al., 2014). This is especially salient for larger transition programs, such as ours, that seek to transcend specific disease populations and subspecialty clinics.

Following a review of all published transition readiness assessment tools in the literature, the steering committee selected the UNC TR_xANSITION Index, which has been objectively deemed to be a well-established, validated instrument (Parfeniuk et al., 2020). We specifically chose the UNC TR_xANSITION Index over other transition readiness measures because it allows clinicians to directly assess a patient's true abilities, rather than their self-report of their abilities. As previously mentioned, self-reported measures are vulnerable to social desirability. This can result in an overestimate of one's true skills and abilities and missed opportunities to address true deficits (Ferris et al., 2012). In our own clinical experience, we've found that asking patients to "show" their knowledge or a skill has much more clinical utility than asking them to "tell" us whether they know something without verifying their report.

Upon selection of the UNC TR_xANSITION Index, health informaticists transformed this pen-and-paper measure into a PowerForm, Cerner's electronic template for capturing discrete data elements in a patient's

EMR. In addition to a word-for-word transformation of the measure into the PowerForm, we also desired: automatic scoring of the measure, the ability to pull data gathered from the measure into our transition registry, and an “at-a-glance” summary of each patient’s transition readiness across the 10 domains of the UNC TR_xANSITION Index. For this high-level cross-domain view, we leveraged a stoplight color scheme to indicate if the patient had achieved full mastery (green), partial mastery (yellow), or no evidence of mastery (red) of a domain. See Figs. 1 and 2 screenshots of the Cerner PowerForm and “at-a-glance” summary.

Intervention

Four subspecialty condition-specific populations were selected to test the transition PowerForm: epilepsy, IBD, type 1 diabetes, and oncology survivorship (Table 1). Each clinic was specifically selected by the steering committee due to its unique patient population. Epilepsy and IBD were in the first wave of PowerForm testing. Epilepsy is our largest chronic illness population. Patients are generally medically complex and have a high incidence of co-occurring IDD. Most studies on transition readiness exclude patients with IDD yet these may be the patients with the greatest need for assistance with transition (Zhang et al., 2014). IBD, our second population, has a mean age at time of diagnosis of 15 years (Kugathasan et al., 2003). Because this age is well after the recommended age by which transition programming should begin (i.e., 12 years), many patients with IBD undergo an “accelerated” transition process. Compared to our epilepsy population, IBD patients are generally neurotypical and have fewer medical complexities and psychosocial needs.

Our second wave of PowerForm testing included type 1 diabetes and oncology survivorship. Type 1 diabetes has two peaks of diagnosis (4–7 years and 10–14 years) (Mayo Clinic, 2021). Therefore, most patients are diagnosed prior to transition initiation (i.e., age 12). These patients are expected to have a more “typical” transition experience. In addition,

diabetes clinic provided the opportunity to test the form with a patient population whose illness requires intensive daily self-management. Unlike our other clinics, which are primarily sole-provider-led, the diabetes clinic, operating in a team-care model, allowed us to test feasibility across three clinicians. Finally, our oncology survivorship population provided the opportunity to test the form with patients who no longer have an acute diagnosis but require lifelong surveillance and screening interventions.

Prior to adopting the measure in the clinical setting, members of each clinical team (see Table 1 for list of team members) underwent two one-hour trainings led by the transition team. Training focused on: (1) Identifying the answers sufficient to award a “correct” response on the form, (2) Problem solving how to integrate PowerForm completion given each clinic’s unique workflow and resources, (3) Introducing transition readiness assessment to patients/families, and (4) Approaching assessment of patients with IDD. Regarding the latter, the literature shows that patients with IDD are more likely to be excluded from transition assessment and planning when compared to their neurotypical peers (Cheak- Zamora et al. 2013, 2014; Rast et al. 2018). Parents and providers often underestimate the abilities of youth with IDD, which can result in lower academic and vocational attainment as well as lower quality of life (Eilenberg et al., 2019). For these reasons, patients were not excluded due to a diagnosis of IDD and instead, if a patient was unable to participate due to a significant cognitive limitation (e.g., non-verbal), caregiver readiness was assessed.

Study of the Intervention

All teams were asked to complete the form with at least 10 patients. Eligible patients were those who were: 1) age 12 and older, 2) six or more months post-initial diagnosis, and 3) attending a scheduled appointment in one of our four clinics. To minimize the potential burden of integrating a new form into clinical care, instructions were

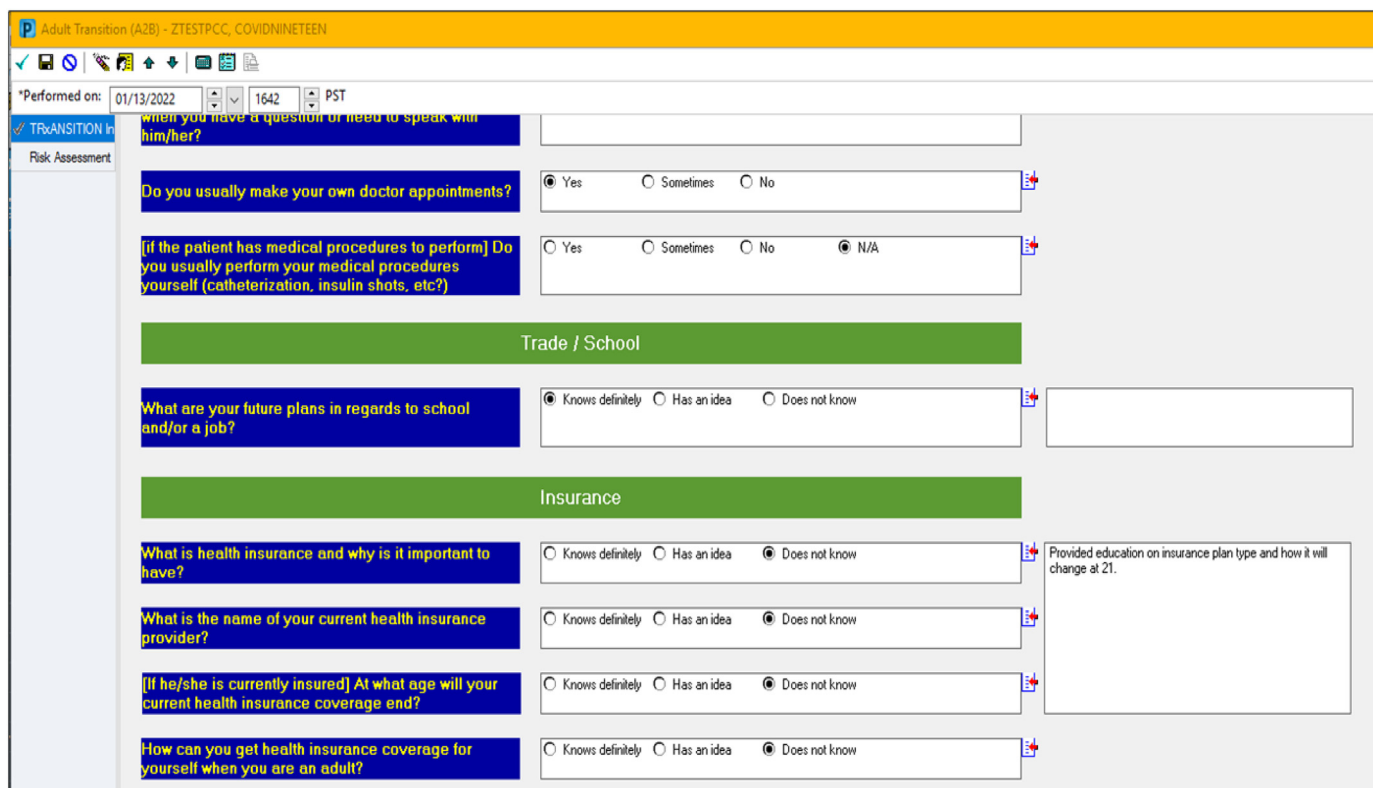


Fig. 1. Excerpt of Cerner UNC TR_xANSITION INDEX Powerform.

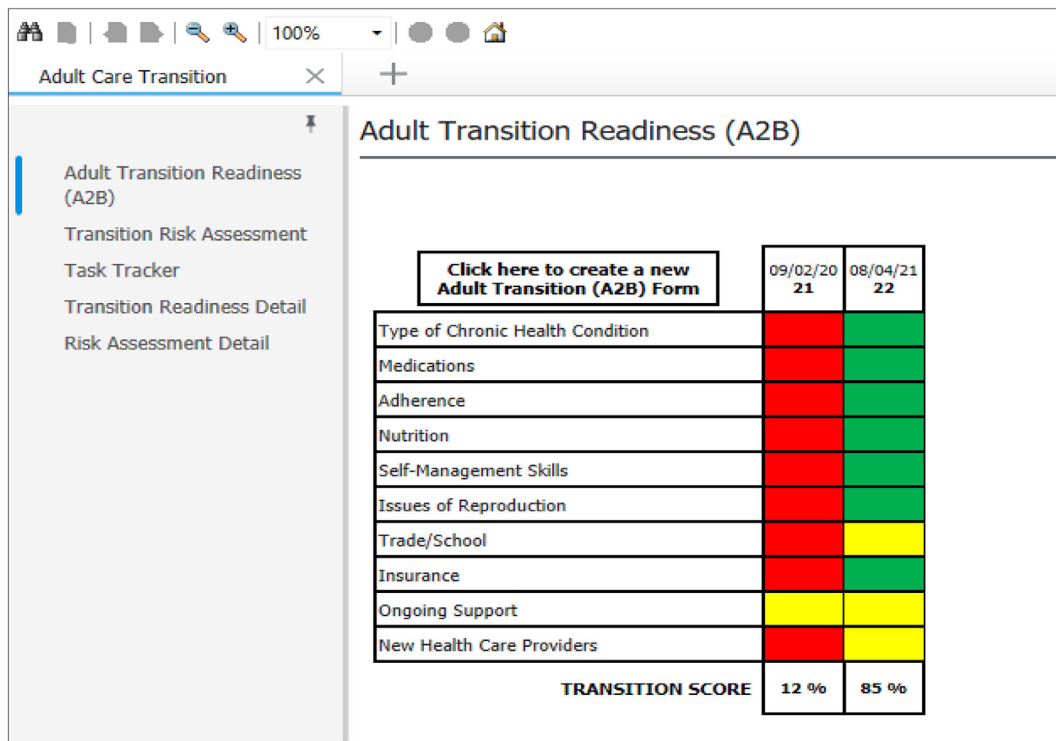


Fig. 2. At-A-Glance Summary of fictitious patient's UNC TR_xANSITION Scores.

customized to each clinic (See Table 2). Clinics varied in frequency in which they were held, with some clinics running several times a week and others only twice a month. To allow sufficient time for all clinics to meet program objectives, our implementation trial was set to four months per clinic. Lessons learned from the epilepsy and IBD teams' ability to comply with this request informed goals modifications for our diabetes and oncology survivorship teams. For example, we learned that even in clinics with a high number of patients and busy providers (i.e., epilepsy, diabetes), it was better to set specific goals rather than general ones (i.e., complete the form with a specific # of patients per clinic session vs. complete whenever possible). Steering committee members were present during the first few clinics in which the measure was tested to answer questions and provide support to the clinical team.

Thereafter, a member of the transition team met with clinical team members as needed to monitor progress, obtain feedback, and problem-solve any challenges experienced.

Measures

Transition Readiness Assessment. The UNC TR_xANSITION Index is a 32-item clinician-completed measure assessing youth transition readiness relevant to each patient and broader transition readiness skills across 10 domains: Type of illness, Rx (medications), Adherence, Nutrition, Self-management, Issues of reproduction, Trade/school, Insurance, Ongoing support, and New health providers (Ferris et al., 2012). The UNC TR_xANSITION Index uses open-ended questions to assess patients'

Table 1
Overview of clinics.

	Epilepsy	IBD	Diabetes	Oncology Survivorship
Approx. # of transition-age patients	1793	129	961	295
Typical length of visit	30 min	90 min	120 min	120 min
Typical frequency of visits	6–12 months	6 months	Quarterly	Annually
Payor Mix				
Public insurance	59.12%	41.09%	49.43%	46.10%
Private insurance	38.54%	57.36%	48.70%	51.19%
Self-pay	1.62%	0%	0.73%	1.02%
Military/Government	0.61%	0.78%	0.62%	1.02%
HSM	0%	0.78%	0%	0%
Other/unknown	0.11%	0%	0.52%	0.68%
Providers in Clinic	Neurologist	Gastroenterologist Dietician Social Worker Psychologist Nurse Coordinator Research/QI	Endocrinologist CDE Dietician Social Worker TC	Oncologist Nurse Practitioner Social Worker Psychologist Dietician Research Assistant Medical Assistant Case Manager
Individual(s) completing PowerForm	Neurologist	Gastroenterologist OR Dietician + Social Work/Psychology	Endocrinologist + TC OR CDE	

Note: HSM = health sharing ministry; CDE = Certified Diabetes Educator; TC = Transition Coordinator.

Table 2
Feasibility and acceptability summary.

	Epilepsy	IBD	Diabetes	Oncology Survivorship
Total of 10 PowerForms Completed?	Yes	Yes	Yes	Yes
Assessment Rate Goal	Whenever possible	2 forms per clinic	1 form per clinic	First 10 patients with acute lymphoblastic leukemia presenting to clinic
Rationale for Assessment Rate Goal	Very short appointments for complex patients; limited nursing and ancillary staff to assist	Highly staffed clinic; smaller number of patients per clinic session; longer appointment times	High number of patients per clinic session; multiple providers competing for face-to-face time with patients	Highly staffed clinic; longer time between appointments; oncology team chose to focus on a specific diagnosis for this assessment
Effectiveness Rate (# patients assessed/#patients eligible for screening)	N/A	66.67% (10/15)	90.9–100% (10/10–11)	100% (10/10)
Patient/Family Refusal	0%	0%	0%	0%
Adoption of PowerForm Post-Pilot Testing	No; Adoption pending care model redesign	Yes; Full Adoption	Yes; Partial Adoption	No; Adoption pending form revisions

actual knowledge, which can be cross-referenced with the medical record for more accurate assessment. The measure takes approximately 5–7 min to complete. For each question asked, the clinician must rate the patient's response as Correct/Knows Definitely (1 point), Non-specific/Has an idea (0.5 points), or Incorrect/Does not know (0 points). Points are averaged by domain and then summed to generate an overall transition readiness score ranging from 0 to 10, with higher scores suggestive of greater transition readiness.

Provider feedback. A feedback questionnaire, created for this study, was distributed via an online data collection tool (REDCap) to all individuals in the clinics who initiated a transition form in the EMR. Multiple choice questions inquired about the user's experience with the PowerForm, most and least useful domains, and overall usefulness and clinical utility. Recommendations for improvement were also solicited via a write-in option.

Analysis

Feasibility was measured in two ways: 1) whether clinics tested the form on a minimum of 10 patients within a 4-month period and, 2) the assessment rate (# of eligible patients with completed forms / # of eligible patients seen in clinic). While our first feasibility measure had an objective benchmark for success (i.e., whether the goals of assessing 10 patients was met), we could find no benchmark in the literature for an acceptable rate of assessment for a new clinical protocol. Thus, we set our benchmark assessment rate at 50% and examined its variability across clinics to generate hypotheses regarding factors enhancing or hindering it.

Acceptability was evaluated in several ways: 1) the percentage of patients/families who refused assessment, 2) an anonymously completed staff feedback questionnaire, and 3) adoption of the form into clinical care (i.e., whether clinics continued to independently use the form after completing the PowerForm with 10 patients). We aimed for a low patient/family refusal rate (<10%).

Ethical Considerations

The current project was reviewed by the governing institutional review board and classified as “exempt.”

Results

Feasibility

Feasibility was assessed in two ways. Overall results across clinics are presented below and summarized in [Table 2](#).

Feasibility Measure #1: Ability to meet goal of PowerForm testing with 10 patients

All clinics were able to meet this goal.

Feasibility Measure #2: Assessment rate

Our assessment rate measured how efficiently our teams were able to reach the target goal of 10 patients. This was measured by dividing the number of eligible patients with completed forms by the total number of eligible patients seen up until reaching the target goal. Our assessment rate goal was 50%.

An assessment rate for the epilepsy clinic could not be calculated as this team was not given a measurable goal for form completion. Factors contributing to the lack of a measurable goal included limited clinic staffing (ambulatory visits include physicians only with nursing follow-up as needed by phone), staff attrition resulting in the loss of three epileptologists, and a care model redesign.

The IBD team was given the goal of assessing two patients per clinic session. Their overall assessment rate was 66.67% ([Table 2](#)). Following completion of their goal, the IBD team provided feedback that adapting their clinic procedures for only two patients was difficult as it placed more demands on the team to remember which patients required special consideration.

The diabetes clinic tested feasibility across three providers, who each completed the form with 10 patients. Overall, providers often exceeded their goal of one patient per clinic. Their average assessment rate was 93.93%.

The oncology survivorship clinic assessment rate was 100%. The oncology survivorship clinic model already included patient assessments as part of the workflow. This allowed for quick adoption of the PowerForm by staff who were familiar with completing assessments as part of the visit.

Acceptability

Acceptability Measure #1: Patient/Family refusal

No patients/families in any of our clinics refused to answer PowerForm questions. Our refusal rate of 0% was below our goal of <10% refusal.

Acceptability Measure #2: Clinician-completed survey

Seventeen healthcare providers who used the PowerForm were invited to complete an anonymous online survey designed to gather information about their experience using the PowerForm. Of these, 10 completed the survey (59% completion rate).

User experience. Of the 10 users who completed the survey, one reported that it took “less than 5 minutes,” six reported “less than 10 minutes,” and three reported “greater than 10 minutes.” Most

respondents seven out of 10 reported completing the PowerForm in its entirety, as opposed to only those sections relevant to their role on the medical team (e.g., dietician only asks nutrition questions).

Usefulness of specific domains. Respondents were asked to identify the domains they found most and least useful when assessing patient's transition readiness. Respondents could vote for as many domains as possible for these questions. The most useful domains were: R_x - medication understanding (selected by nine out of 10 respondents), adherence (eight out of 10), self-management (eight out of 10), issues of reproduction (seven out of 10), and new health providers (seven out of 10). Domains rated least useful were: Nutrition (four out of 10) and Trade/School (three out of 10).

Overall usefulness and clinical utility. One hundred percent of respondents indicated that the PowerForm helped them identify knowledge gaps in their patients. Regarding use of the PowerForm with patients with IDD, most providers (66.67%) reported they did not assess any patients with IDD. Of the three users who used the form with this population, one reported it was "very easy" (33%) and two reported it was "somewhat easy" (67%) to complete the form.

Recommendations for improvement. Six respondents provided written responses for how to improve the form. Three respondents recommended breaking up the form based on the patient's age, rather than asking all questions. As one respondent stated, "*Identifying age-appropriate questions (i.e., Should 12-year-olds be asked about reproduction?); I've noticed also some patients can feel like they are being quizzed if they are responding 'no' to several questions in a row and will often apologize for not knowing the information even though it's completely age-appropriate for them not to know yet.*"

Another respondent provided recommendations to better integrate assessment findings into clinical care. These recommendations included integrating findings with one's progress note and having different documents/resources embedded in the form that could be easily printed and shared with families to address the specific knowledge gaps identified. For example, if the assessment revealed that the patient had limited knowledge about the impact of their health condition on their reproductive health, the clinician could access educational materials related to this topic directly within the PowerForm.

Another respondent recommended eliminating the partial credit (0.5 points) rating option on the form, stating "*Either they know, or they don't know!*" Finally, one respondent commented that some of the questions were repetitive; however, no additional information was provided to help identify which questions.

Acceptability Measure #3: Adoption of PowerForm

Half of our clinics (i.e., IBD and diabetes) continued to use the form after reaching their target goal and integration of the PowerForm into the clinical workflow has evolved with time. The IBD team struggled to complete the form on low-staffed clinic days. It took approximately three months after completion of the PowerForm with the first 10 patients for the IBD team to fully integrate transition readiness assessment into clinical flow for all eligible patients. This only occurred when transition readiness was included as a metric in the pre-visit planning documents prepared prior to each IBD clinic. For the diabetes clinic, a few patients are selected for assessment per clinic session, however, lower assessment rates occur on very busy clinic days. Regarding the two clinics who did not adopt the PowerForm after the trial, the oncology survivorship clinic chose to postpone adoption until a revised version of the form that incorporated user feedback was rolled out. The epilepsy clinic acknowledged the importance of transition assessment and intervention, but limited ancillary staff to assist with assessment, high patient volume, and fear of neglecting clinical care given clinic time constraints, postponed the formal adoption of the PowerForm until completion of clinic redesign.

Discussion

Summary

This project adds to the limited literature on EMR-integrated transition readiness assessment. As previously discussed, EMR integration provides numerous benefits over current pen-and-paper methods of assessing transition readiness. We evaluated the feasibility and acceptability of our measure across four subspecialty clinics. Our clinics differed from one another in terms of staffing, length and frequency of clinic visits, patient medical complexity and self-management demands, and length of the transition process. This heterogeneity may increase the generalizability of our findings to other settings. Our testing of the form in populations with IDD is also a strength. Most studies on transition readiness exclude patients with cognitive impairment yet these may be the patients with the greatest need for assistance with transition. Our experiences testing our form with this population will spur additional research to inform improvement of our assessment approach, such as using machine learning to guide clinician-decision making regarding who to assess and when/how to educate and intervene.

Interpretation

Feasibility was examined in terms of each team's ability to complete the assessment with 10 patients and how well they were able to integrate the transition readiness assessment into clinical care for eligible patients (i.e., assessment rate). While all clinics were able to meet our first benchmark, our assessment rate varied from 67 to 100%. Implementation of our assessment was feasible but required resources beyond what currently exist in sole-provider clinics. Those clinics with the highest assessment rates tended to have multidisciplinary teams, longer appointment times, and less medically complex patients. Unfortunately, our design precluded our ability to identify if one specific factor, or a combination of factors, contributed to higher acceptance rates. One would naturally assume that assessment rates would be lowest among those clinics with the most medically complex patients, shortest appointment times, and fewest staffing resources, as was the case in our epilepsy clinic. However, we must note that all teams reported finding value in this work and were willing to continue incorporating transition assessment into clinical care, pending changes to the form or their care model.

While assessment of transition readiness in our epilepsy clinic was challenging, it was critical to include this population due to the underrepresentation of individuals with chronic conditions and co-occurring IDD in the literature. In assessing these individuals, we encountered two major challenges: 1) deciding whom to evaluate (i.e., patient or parent), and 2) prioritizing transition readiness considering other pressing concerns. Parental assessment was clearly indicated in the presence of severe patient incapacity (i.e., patient is unable to communicate with examiner and/or profoundly delayed). However, in situations in which the patient demonstrated some level of cognitive capacity, assessment decisions were made at the clinician's discretion. While assessing both the parents' and patient's skills would allow for the most comprehensive and helpful assessment, this approach is likely not feasible given challenges experienced conducting a single assessment in clinic. The second barrier encountered was competing clinical concerns. When patients are medically complex and seen less frequently, the number of issues to be addressed at a single visit can often exceed the time available. A way to address this, proposed by the clinical team, is to have a planned comprehensive transition visit annually that would allocate both time (e.g., 15 additional minutes) and resources (e.g., social work or care management) to be made available to assess transition readiness and provide necessary education.

Regarding acceptability, no patient or family declined answering questions related to transition. Several factors may have influenced our low refusal rate. First, families may be more willing to answer

questions when in a clinical setting. Second, many of the questions on the assessment overlap with those clinicians would ask as part of their routine assessment, families may not have noticed a significant difference in their care. Finally, our introduction of the assessment may have influenced our low refusal rate. It is not uncommon for providers to use the term “transition” when they are referring to “transfer” (i.e., “it is time for you to transition to adult care”). As a result, the word “transition” has developed a negative connotation. When our staff introduced the purpose of the transition readiness assessment to patients and families, we explained that this was a new feature being implemented as part of their routine care and a broader system-wide initiative to better prepare our patients and families for their eventual graduation from the children’s hospital. Staff introduced our transition policy and emphasized that: 1) transition is a process, not an event, 2) it begins in early adolescence and, 3) longitudinal assessment of skills allows us to gradually help patients and families build the skills they need to manage their health into adulthood.

Our clinician-completed survey revealed generally positive information regarding the use of the PowerForm and its ability to identify patient knowledge gaps. This survey also identified areas for improvement, which were further explored in an informal 2.5-h workgroup session with individuals who had completed 10 or more PowerForms in Cerner. The workgroup began by reviewing the results of the clinician-completed survey, then discussing potential changes to the PowerForm to improve clarity and increase efficiency while protecting the psychometric integrity of the measure. As a result of survey feedback and our workgroup, comment boxes were added to allow providers to note specific details learned through the assessment and/or educational interventions provided in response to identified deficits. With the form creator’s permission, the form was also divided into two parts: Beginner Skills and Advanced Skills.

Beginner Skills focus on disease knowledge and self-management skills appropriate for youth in early-to-mid adolescence as well as those recently diagnosed. This section includes the following UNC TR_xANSITION Index domains: Type of Illness, Rx (medications), Adherence, Nutrition, Issues of reproduction, Ongoing support. In contrast, Advanced Skills domains are typically mastered in mid-to-late adolescence (Zhong et al., 2018) and are more appropriate for patients who will transfer to adult care within the next few years (i.e., Self-management, Trade/school, Insurance, and New health providers). Dividing the form into two parts reduces administration time and promotes developmentally appropriate and targeted assessment. This revised approach to form completion will soon be integrated into patient care, and we will explore ways to optimize age-appropriate readiness assessment. Of note, reproductive health may be considered an “advanced topic” more appropriate for older adolescents; however close to one-third of adolescents have had sexual intercourse by the age of 16 (Abma & Martinez, 2017). Additionally, our clinicians emphasized the need to discuss reproduction in early adolescence as some medications used to treat their patients are teratogens.

Limitations

Results from this project should be considered in the context of its limitations.

Although we tested our form across four distinct clinics, all operated within the same healthcare system. Thus, our results may not be generalizable to settings or clinics with different patient demographics and resources. Our small sample size and varied criteria for PowerForm implementation also affects generalizability. In total, 60 PowerForms were completed across our four clinics. Criteria for completing the form varied by clinic. This limits generalizability yet critically speaks to the fact that there is no “one-size-fits-all” approach when implementing transition programming. Just as each patient has unique needs, so does each clinic. It is critical to consider each individual clinic’s unique structure, resources, and barriers when integrating a new clinical practice. All

but one of our clinics was multidisciplinary, which may have aided in feasibility. Although most clinicians reported that completion of the PowerForm took <10 min, we recognize that adding 10 min to a clinic visit may not be feasible in those clinics with numerous patients and very short appointment times. As our goals for form completion were conservative (i.e., a few patients per clinic), it is likely that implementation rates would be lower when a greater number of patients require assessment. However, now that transition readiness assessment has routinely been incorporated into the clinic flow for the IBD team, the number of patients requiring assessment on any clinic day generally reflects the conservative goal we established for the team (i.e., approximately two patients per clinic session).

Conclusions

From an implementation science standpoint, we offer recommendations for colleagues interested in adopting an EMR-based transition assessment. As our project demonstrated, implementation is more feasible in clinics that are well-staffed and have lengthier patient visits. Thus, when selecting divisions/clinics for implementation, we recommend a strategic focus on divisions/clinics where transition work is viewed as meaningful (e.g., physician and nursing champions exist) and doable. Selecting clinics with a well-defined workflow and focusing on incorporating incremental changes may also enhance implementation and adoption. For example, rather than introducing the entire assessment, staff may initially be asked to complete a portion of the form, such as the 1–2 most meaningful domains for the patient population or those domains classified as “Beginner Skills.” As familiarity and comfort increase, additional portions of the form can be integrated into clinical care.

To expand upon our work and continue to advance the field of transition to adult care, several areas of research remain. As previously mentioned, unfunded work is a major barrier to providing comprehensive transition care. While the reimbursement for time spent assessing patients’ transition readiness may help, engagement with various payors is needed to further explore payment models that will make this work sustainable and cost-effective. We’ve engaged in discussions with the major payor groups in our county to advocate for reimbursement of our services and have made some progress billing for specialized transition visits and formalized assessment using the UNC TR_xANSITION Index. Demonstrating the clinical and financial effectiveness of such work through improved patient health outcomes and reduced healthcare expenditures, may help bolster the argument for healthcare funding. However, data supporting the efficacy of transition programming are scarce due to the need to follow patients before, during, and well after their transfer into the adult healthcare system. Multi-year longitudinal assessment of transition readiness is also needed to help identify factors that enhance or hinder transition readiness, evaluate the efficacy of transition interventions, and examine the tool’s predictive validity for key outcomes (i.e., disease status, health care utilization, patient/family satisfaction, completion of transfer). Such data would guide the refinement of future intervention efforts, provide stronger justification for reimbursement of services, and enhance our ability to provide evidence-based care for our patients and their families.

CRedit authorship contribution statement

Wendy N. Gray: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft. **Lauren Partain:** Conceptualization, Formal analysis, Writing – original draft. **Erin Benekos:** Conceptualization, Formal analysis, Writing – original draft. **Kenneth Grant:** Conceptualization, Data curation, Writing – review & editing. **Michelle Kennedy:** Conceptualization, Data curation, Writing – review & editing. **Parasto Dorriz:** Data curation, Writing – review & editing. **Anne Carpinelli:** Conceptualization, Writing – review & editing.

Karina Chavez: Data curation, Writing – review & editing. **Christine Yun:** Data curation, Writing – review & editing. **Lilibeth Torno:** Data curation, Writing – review & editing. **Daniel Shrey:** Data curation, Writing – review & editing. **Mark Daniels:** Data curation, Writing – review & editing. **Michael Weiss:** Conceptualization, Writing – review & editing.

Declaration of Competing Interest

None.

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