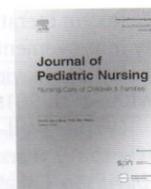




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Advancing pediatric primary care practice: Preparing youth for transition from pediatric to adult medical care, a quality improvement initiative

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ABSTRACT

Background: Despite well-known guidelines to prepare adolescents to transition to adult care, research has shown that this is done less than 25% of time in pediatric practice. This quality improvement (QI) project aimed to improve the transition readiness process for all adolescents aged 14–18 at health care maintenance visits.

Methods: A multidisciplinary team conducted a quality improvement initiative in a large, urban pediatric academic teaching practice serving a low-income, multi-ethnic population. The team developed transition interventions through successive Plan-Do-Study-Act cycles. They included a formal transition readiness assessment tool, provider-delivered education related to transition readiness, and delivery of a transition brochure for all adolescents. The team used run charts to follow the rate of formal transitions discussions documented in the electronic medical record.

Results: Over the course of 36 months the outcome measure of provider documented transition readiness discussions increased from 19 to 64% of the time. Over the same course of time, the process measures of transition brochure distribution and completion of the readiness assessment tool increased from 0 to 94% and 0 to 84% respectively.

Conclusions: QI methodology and multidisciplinary coordinating to streamline workflow, distribution of transition information, readiness assessment and provider discussion and documentation can be successfully incorporated into a busy primary care setting. By formalizing and standardizing the transition readiness process, pediatric providers can improve young adults' readiness to transition to adult medical care.

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Introduction

Youth with and without special health care needs are a vulnerable population between the time that they age-out of pediatric care until they transfer to and firmly establish adult-oriented healthcare. They often get lost to follow-up, do not have a medical home, use the Emergency Department (ED) for primary care needs, are hospitalized unnecessarily, and have a high rate of morbidity and mortality (Davidson, Chhabra, et al., 2015; Davidson, Doyle, & Silver, 2015; Graves et al.,

2019). Guidelines and reviews have outlined how to improve adolescent preparation; the process of planning transfer to adult medical care known as health care transition (HCT) for youth with and without special health care needs (Cooley & Sagerman, 2011; White & Cooley, 2018). Recommendations include starting the preparation early, providing written information to patients/families about transition, and using a transition readiness tool to assess the patient's knowledge and preparation. Improved provider-initiated discussion with patient/family of HCT and preparation for transition (including understanding a patient's medical knowledge) has been a goal of Healthy People 2020 and Healthy People 2030 and one of the indicators of HCT planning in the national survey of children's health (The Office of Disease Prevention and Health Promotion, 2022a; The Office of Disease Prevention and Health Promotion, 2022b). Reviewing and addressing the gaps in knowledge determined by a transition readiness tool is recommended by published guidelines and is included in the six core elements of Got Transition (White et al., 2018; White, Schmidt, Shorr, Ilango, Beck, & McManus, 2020).

Abbreviations: HCT, Health Care Transition; PCC, Primary Care Clinician; LCSW, Licensed Clinical Social Worker; PSR, Patient Service Representative; PDSA, Plan Do Study Act.

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Recent literature has emphasized the importance of the use of quality improvement (QI) projects and methods in advancing health care transition provider practice (Mahan et al., 2017; Quinn et al., 2020; White et al., 2018).

Despite well-documented HCT improvements in the literature for over thirty years, there remains a significant gap in provider practice (Davidson, Chhabra, et al., 2015; Magrab & Millar, 1989). The most recent National Survey of Children's Health (2019–2020), completed by parents, found that only 17.6% of 12–17 year olds received the HCT services recommended (The Child Adolescent Health Measurement Initiative, 2020). A 2011 study of New York State pediatricians evaluating pediatrician HCT practices showed only 3% of pediatricians started transition planning at the recommended age (12–14 years) and only 34% identified core knowledge and skills (i.e., transition readiness) (Davidson, Chhabra, et al., 2015). Similarly, a 2013 study of provider practice in an urban academic medical center showed that only 23% identified core knowledge and skills for their youth with special health care needs (Davidson, Chhabra, et al., 2015; Davidson, Doyle, & Silver, 2015). In that study, those who used standard forms to guide transition preparation were more likely to be compliant with steps to assist patients in the transition process. Use of standardized tools encourages targeted provider-delivered education and discussion of transition readiness with youth and their families. Other studies show that using a structured process has been shown to improve HCT and improve providers' use of recommended steps such as the six core elements from Got Transition (Jones et al., 2019; Schmidt et al., 2020).

At our practice site, prior to this work no standardized tools were being used to assess core knowledge and skills. It was unclear when healthcare transition education was commencing, and what education about the healthcare transition process our primary care providers were giving to patients and families. A six-month review of informal provider practice revealed that only 19% of the PPCs had informally documented any discussion of elements of healthcare transition.

This QI project assessed the impact of distribution of a transition brochure and consistently incorporating a formal transition readiness assessment tool for all adolescents ages between 14 and 18 years during their health care maintenance (HCM) visits, in order to improve provider-delivered education related to transition readiness. Our primary aim was that 75% of youth 14–18 years who come for a HCM visit will have a discussion with their Primary care clinician about at least one element identified by the transition readiness tool.

Methods

Context

This QI project was conducted in a large urban academic teaching practice serving a low-income, multi-ethnic population. Approximately 26,000 patients are seen annually; 21–22% are youth between 13 and 18 years old. This is a multilingual population with English and Spanish as the most common languages spoken. Pediatric providers see patients in a medical home using a continuity of care model. The practice is hospital-based, with a mix of patients with and without special health care needs.

Intervention

From January 2017 through December 2019, a representative multidisciplinary team was assembled comprised of chronic care registered nurses (2), licensed practical nurses (2), one LCSW, two PSRs, and two PCCs who met once or twice a month. Administrative staff (nursing supervisor and clerical supervisor) later included on the team provided perspectives and insights when changes in environment and roles of staff were contemplated. Following classic QI methodology, interventions were trialed, effectiveness assessed, and spread, stopped, or modified accordingly (PDSA cycles).

A transition brochure was developed in 2012 internally by the health center. The brochure was based on national recommendations on information that should be communicated to patient, parent, and pediatricians on their roles in the HCT process (White & Cooley, 2018). This brochure, available in English and Spanish, was developed with input of families, patients and staff (PCCs, nurses, LCSW, and PSR) and is a proxy for a practice transition policy. Despite its availability, it was rarely used in the practice prior to the onset of the project.

A nationally available and widely used healthcare transition readiness tool (www.gottransition.org) available in English and Spanish was adapted for project use. It includes questions related to patient's knowledge of healthcare and access to medical care. Information added to the original tool for our practice included: an introduction to patient/parent, a check-off whether transition brochure was received, and patient listing of any chronic illnesses.

The transition readiness tool and brochure were given to the target patient population annually during their HCM visits by the front desk staff or nurse upon check in for appointment. The tool was completed by youth alone, or with assistance of parent depending on patient's ability and was given to the PCC by the patient or placed in the patient's medical folder for review. After reviewing the tool, the PCC discussed any patient gaps in knowledge or access to care gaps that were identified by the tool.

Study of the intervention

Using a random 20% convenience sample of patient charts, we obtained baseline data to determine the average of 14–16 year olds who are seen in the practice over six months (July–December 2016) for whom the providers documented discussions about transition readiness at these visits as well as cycle time ($n = 73$). The intervention was implemented, and measures were collected prospectively starting February 2017 until December 2019 (3183 charts total reviewed in the electronic medical record (EMR)). The project initially included only 14–16 year olds, and then in September 2018 the project was expanded to include 17–18 year olds. Initially, English speaking youth and parents were included, and in January 2018 the project was expanded to the Spanish speaking population. Prior to the start of the project, 100% of PCCs surveyed stated that they always discussed at least one element of the transition readiness tool during their adolescent HCM visits. However, baseline chart reviews indicated that only 19% of charts had informally documented some discussion of one or more of the elements in the transition tool.

Measures

The outcome measure was PCC documentation of HCT discussion in the EMR. Process measures for this project were the distribution of the brochure to the patient/family and completion of the transition readiness tool by the patient/family. Table 1 provides definitions of project outcome and process measures.

During the project, three surveys were administered to the PCCs: at baseline, midpoint, and the end, and a survey was administered to the nursing staff at midpoint (Table 2). The baseline PCC survey inquired about recalling transition advice given to a recent patient using the transition tool as a model. The midpoint PCC survey focused on barriers to project process and outcome measures and inquired about changes in office procedure that made a difference. The final PCC survey inquired about barriers to process and outcome measures and recommendations to shortening the transition tool. The nursing staff midpoint survey asked about barriers to distribution of brochure/tools, documentation in the EMR, and successful changes in office procedure.

Analysis

The intervention was implemented, and data measures were collected for 36 months prospectively and 3,183 charts were reviewed.

Table 1
Family of measures and measure definitions (outcome and process).

Measure type	Measure concept	Measure definition	Data collection	PDSA's/changes
Outcome	PCP discussion (smart phrase diagnosis codez71.89 or free text)	Percent of audited chart with documented transition readiness discussions / monthly total of charts for health care maintenance visits (HCM) for 14–18 yr. old adolescents	Monthly chart review of all 14–18 year old HCM visits for documentation of transition readiness discussion or referral	<ul style="list-style-type: none"> - Green reminder on existing list of screening tools list attached to computer - Green reminder added to keyboard - Modified keyboard reminder to include diagnosis code and smart phrase - Tool printed on yellow paper - Smart text created for PCCs
Process	Brochures distributed (documentation by patient, nurse or provider.	# of transition readiness brochures distributed/ # monthly total HCM visits for 14–18 yr. old adolescents	Monthly chart review of all 14–18 year old HCM visits for documentation of brochures distributed	<ul style="list-style-type: none"> - Introduction of transition tool - Nursing documentation in the EMR
Process	Readiness Tools completed	Percent of completed Readiness Tools completed/ monthly total HCM visits for 14–18 yr. old adolescents	Completed Readiness Tools collected monthly for all 14–18 year old HCM visits	<ul style="list-style-type: none"> - Nursing documentation in the EMR

Data was collated and analyzed monthly by the authors. Descriptive statistics (mean, median, standard deviation) were used to report primary and secondary outcomes pre and post intervention Data were displayed on run charts. Survey data used descriptive statistics for multiple choice questions and for free text response.

Ethical considerations

Project participants were PCCs (attendings, nurse practitioner, and pediatric residents), nurses, a licensed social worker (LCSW), and patient service representatives (PSRs)/front desk staff ($N = 76$). The QI team used constant encouragement, utilizing systems-focused, and blame-neutral coaching methodology (coaching without blaming people for their mistakes). There were no medical risks in implementing these procedures as they became standard of care. This QI project was

approved by the Institutional Review Board of Albert Einstein College of Medicine/Montefiore Medical Center.

Results

Over the course of 36 months, the project exceeded its goal of 75% for the two process measures: 94% of eligible patients had received a transition brochure ($n = 145$ as of December 2020), and 84% of eligible patients completed the transition readiness tool ($n = 129$ as of December 2020). The primary outcome measure of 75% documentation of a transition readiness discussion by provider in the EMR was not realized. However, the measure improved dramatically from 19% at baseline to 64% ($n = 99$ as of December 2020). (See Figs. 1, 2 and 3.)

The perceived barriers to process and outcome measures noted in PCC surveys were: time to review the information (54% midpoint $n =$

Table 2
Project surveys.

Project phase (Date)	Question type	Respondents (n)	Questions	Results:	Interventions
Baseline 12/2016	Yes/No	Attendings $n = 12$	In the last month have you talked about at least one of the elements listed below during a 14–16 month checkup? Elements provided: 21 statements from transition tool	100% marked yes	
Mid-point 1/2018	Multiple choice and free text	Attendings $n = 13$	Please check off: Barriers to a. Reviewing tool b. Documenting discussion Most successful changes Suggestions for improvement	Barriers: Forgot to document: 69% Tool not received: 62% Time: 54%	Having nurses document in EMR that Tool and Brochure given
1/2018	Multiple choice and free text	Nurses $n = 12$	Questions Barriers a. Distribution b. Documentation Most successful changes Suggestions for improvement	Barriers: distribution of tool and brochure: Time: 50% Forgot to give: 50% Forgot to document: 33%	Nursing review (the huddle) prior to visit and marking visit
Final 1/2020	Multiple choice and free text	Attendings $n = 12$	Questions Barriers to a. Reviewing tool b. Documenting discussion Most successful changes Suggestions for improvement	Barriers: Time: 67% Forgot to document: 58% Tool not received: 50%	Nurses documenting in EMR Computer Reminders (yellow and green)
Final 1/2020	Rating scale	Attendings $n = 12$	Select 5 most useful and least useful tool statements	Identification of top 5 least useful statements	Transition tool shortened to 15 items for ongoing use

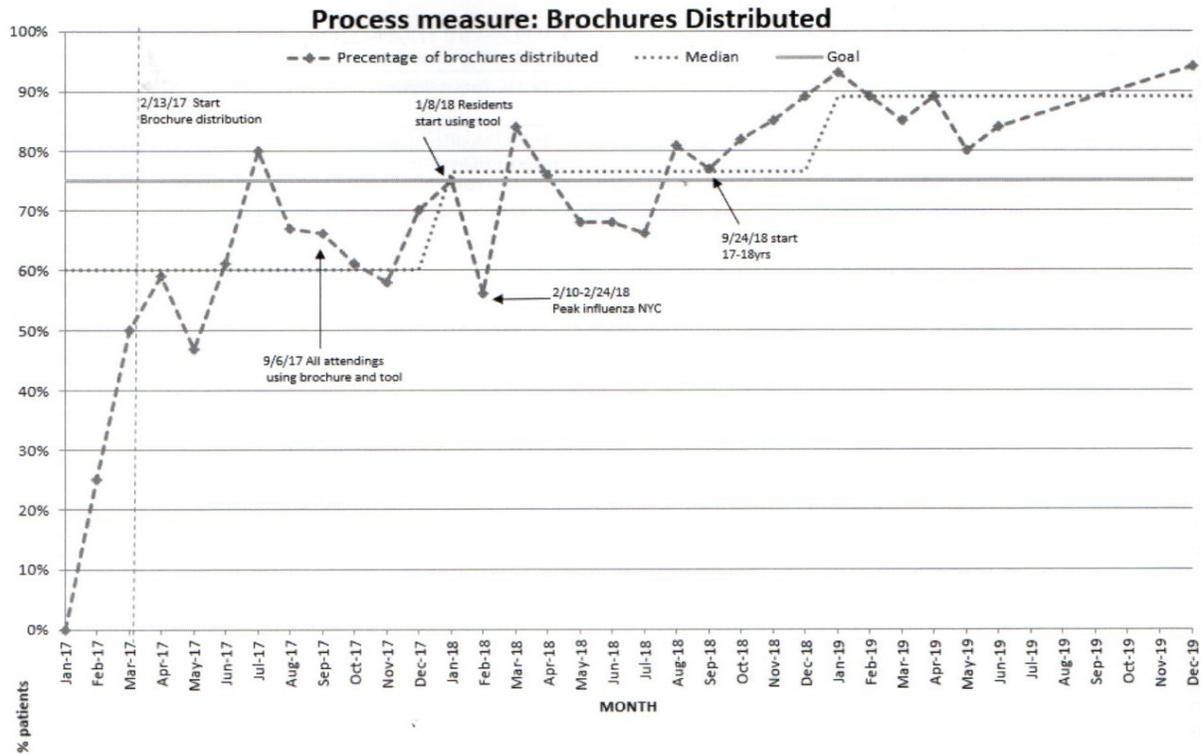


Fig. 1. Process measure: Brochures distributed run chart.

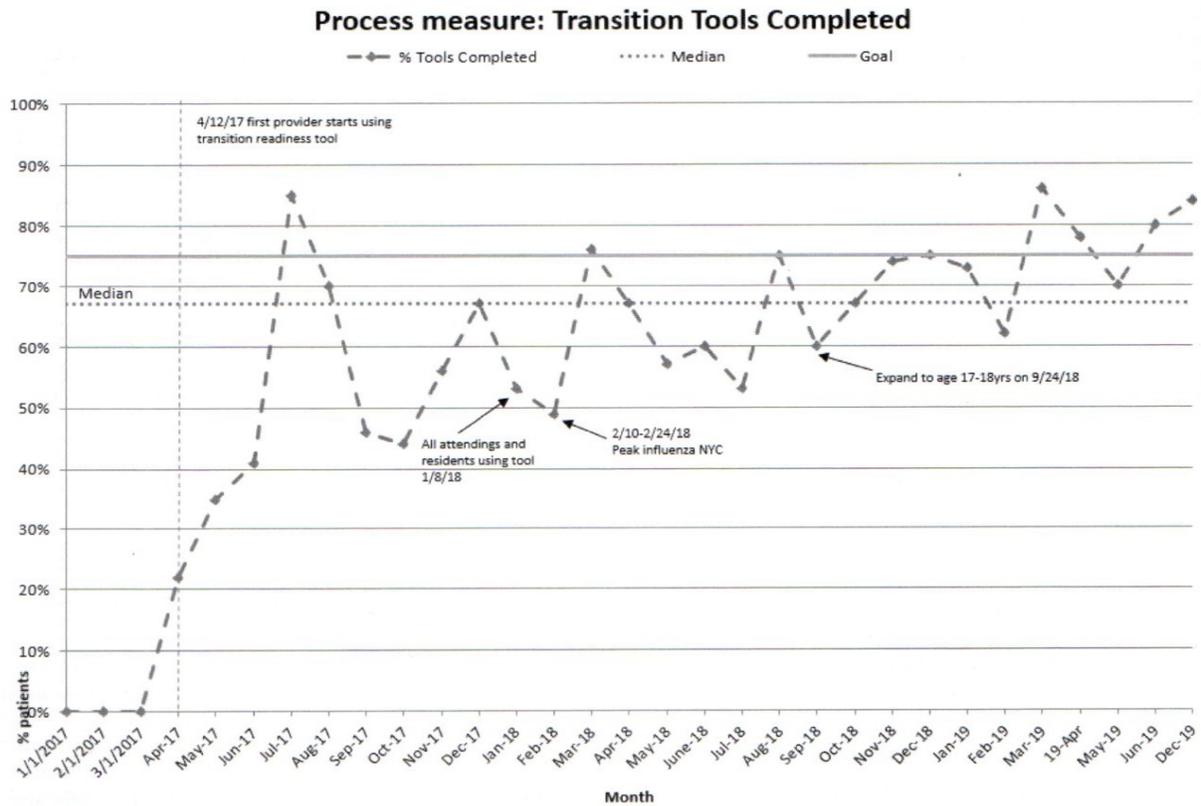


Fig. 2. Process measure: Transition tool run chart.

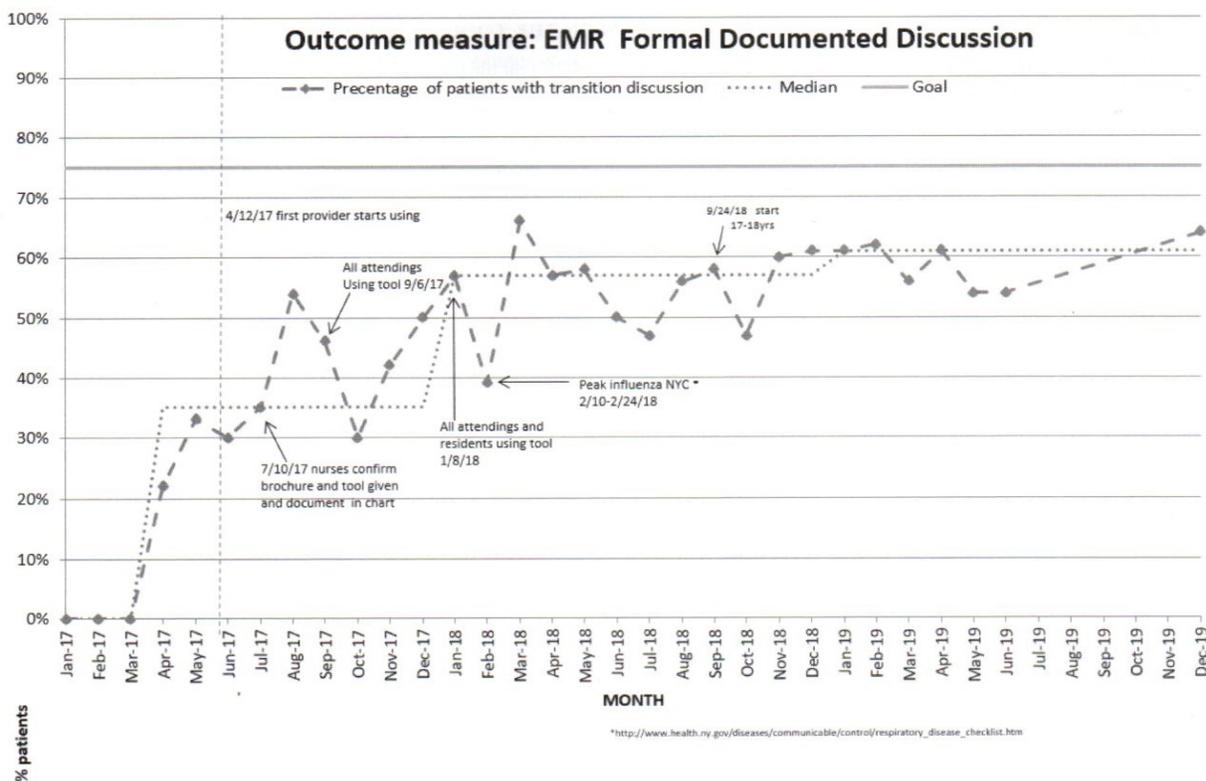


Fig. 3. Outcome measure: EMR documentation run chart.

7, 67% final $n = 8$); remembering to document (69% midpoint $n = 9$, 58% final $n = 7$); and receiving the tools (62% midpoint $n = 8$, 50% final $n = 6$). In the nursing staff survey, the perceived barriers to distribution and documenting included time to document (50% $n = 6$) and forgetting to document (33% $n = 4$). PDSAs are annotated in the process and outcome measures run charts (Figs. 1–3) and Table 1. The survey results are summarized in Table 2.

Training

Training sessions for PCCs began prior to the start of the project including information about the goals of the QI project, the transition brochure, institutional suggested transition guidelines, best practices in transition, how to use the transition readiness tool, resources for transition education, and documentation in the EMR. Other staff members (e.g., nurses, PSR) were trained during team meetings and group meetings. Study data were presented quarterly during department all-staff team meetings. New staff were trained twice a year and new residents yearly. Periodic in-services occurred as needed when there were changes to workflow and tools.

Standardization of workflow

The formal process for distribution and documentation of tools was created using a process map, and was changed iteratively by the multi-disciplinary project team over the duration of the project. A “Quick and easy guide to transition” – recommended by the practice medical director – was created to guide the PCCs’ use of the transition tool and was posted in all exam rooms (Fig. 4). A SmartPhrase was developed to be added to the PCCs’ documentation in the EMR and used in conjunction with the Counseling for transition ICD10 code ((z 71.89) (Fig. 5). The SmartPhrase used drop-down menu selections to confirm discussion of transition and whether or not the brochure had been received.

Visual reminders

Throughout the project, the following reminders were used to increase the uptake of the tools by the staff. A reminder for PCCs to document the appropriate ICD10 code and associated SmartPhrase were added to the transition tool. A sign with the reminder language was added to computer monitors in exam rooms and then moved to the keyboard. The color and shape of the sign were changed three times during the project to combat alert fatigue (Ancker et al., 2017). A poster was created and placed at the registration desk to encourage patient interest and to empower patients proactively to ask for the brochure and tool if not provided initially. The tool was switched from white to bright yellow copies. Despite PDSA data that showed minimal (1%) effect of printing the transition tool on yellow paper, feedback from the second PCC survey attributed the yellow paper as integral to their ability to remember to document per project guidelines. Wall pockets in exam rooms were created to keep extra copies of tools and brochures as another opportunity to access them.

Stakeholder engagement

Quarterly presentations to the entire pediatric department discussed the progress of project including distribution of project run charts. A friendly competition with a prize of catered lunch for the winning group occurred to encourage incorporation of changes in practice. Authors provided individual feedback to pediatric attendings with a letter outlining personal performance of process measures. These data led to the PCC survey on barriers as authors sought to differentiate between clinicians who had higher or lower compliance with documentation. Many of the changes that were successful and sustained were led by nursing staff, including nurses flagging patients in EMR prior to visit during daily interdisciplinary patient huddle and nursing documentation in EMR of patient’s chart that brochure and tool had been given.

YOU ONLY HAVE TO ADDRESS ONE ITEM ON THE TOOL

Here are **FIVE easy** examples how to approach the 14-18 year old patient who has filled out the transition readiness tool.

For those with a medical problem on a medication:

1. Review the names of patient’s medications, doses and when they take them.
(can just have the patient plan to photograph the bottles/inhalers on their phone so that they can remember them)

Circle this item on the transition readiness tool:

I know my own medicines, what they are for, and when I need to take them.

2. Discussed medication/food allergies and make sure patient is aware of them

Circle this item on the transition readiness tool:

I know my allergies to medicines and medicines I should not take.

For those with or without medical problems:

3. Ask them to write down a few questions before the next visits

Circle this item on the transition readiness tool:

Before a visit, I think about questions to ask.

4. Hand them your business card to keep in their wallet or photograph/put on their phone

Circle this item on the transition readiness tool

I know or I can find my doctor’s phone number.

5. Refer to the transition brochure and explain that at age 18 they are an adult and can come into the office alone and that the medical records or information is not shared unless they agree to share that information

Circle this item on the transition readiness tool:

I understand how healthcare privacy changes at age 18 when legally an adult.

Fig. 4. Quick and easy ways to use transition readiness tool.

Discussion

This QI project demonstrates that HCT preparation can be incorporated into a busy urban teaching practice for all patients using standardized protocols. The majority of eligible patients received a transition

brochure (94%) and completed the transition readiness tool (84%), surpassing our 75% goal for both measures. There was substantial improvement (19% to 64%) in formal documentation of discussion/education with the patient by PCCs in the EMR. Documentation in the EMR is a time-consuming process and the adolescent visit has many components that could have been prioritized over the discussion and documentation of HCT. When surveyed, PCCs noted that they did discuss transition at the visit but sometimes forgot to document in the EMR. In addition, screening fatigue may have contributed to not achieving our goal. At the start of the project only one other screen was routine for our target population and by the end of the project two additional screens were incorporated into practice workflow.

Each member of the multidisciplinary team made important contributions to the project and assisted in the acceptance and the incorporation of changes from the various disciplines. In particular, the successful distribution of the brochure and transition readiness tool would not have been possible without the PSRs and nursing staff embracing and incorporating changes into their routine practice. Information gained from surveys distributed to clinicians and nurses, and input from staff during frequent presentations at practice meetings, assisted in the success of the project and ongoing staff engagement. Using classic QI tools and testing small changes to determine what worked enabled the team to re-evaluate the process on a continuous basis. Changes the team thought would make big differences did not always occur when tested, such as targeted posters for staff to distribute brochures and tools and posters reminding patients to ask about HCT. As found in other HCT QI

COUNSELING FOR TRANSITION FROM PEDIATRIC TO ADULT CARE PROVIDER

DISCUSSED TRANSITION ISSUES WITH PATIENT/FAMILY INCLUDING PATIENT KNOWLEDGE REGARDING PERSONAL HEALTH ISSUES AND HOW TO EFFECTIVELY OBTAIN HEALTH CARE

TRANSITION BROCHURE GIVEN: YES
NO

TRANSITION TOOL REVIEWED AND DISCUSSED: YES
NO

Fig. 5. Transition smartphrase from EMR.

projects, support and involvement by the clerical, nursing, and medical administrators was essential for success of the project (McManus et al., 2015).

Reviews of the HCT literature have been critical of manuscripts about HCT interventions for not providing enough pragmatic detail for others to incorporate the interventions into practice. This project has detailed the interventions, successes, barriers, and practice process, which allows for the replication and adaptation of this project thereby offering the potential to spread to other healthcare centers (McManus et al., 2020; Society for Adolescent Health and Medicine, 2020). Published QI research on HCT has focused mainly on youth with special health care needs, subspecialty practices, specific populations, adolescent medicine practices, or transition navigator interventions (Allende-Richter et al., 2021; Okumura et al., 2014; Rusley et al., 2020; Shapiro et al., 2021). Many studies have included an older population close to transfer age rather than early adolescence as recommended. Literature reviews have recommended future studies include patients without special health care needs and detail the improvement process for replication in other sites (Graves et al., 2019; Schmidt et al., 2020).

A number of recently published HCT QI projects have focused on HCT transition for all youth in a variety of general practice settings (White et al., 2018). These studies have focused on an older population (17 and older), EMR integration of health care transition tools, and use of a patient navigator intervention (Allende-Richter et al., 2021; Rusley et al., 2020). Rusley et al. report that in an adolescent medicine practice they did not have good acceptance of the readiness tool incorporated into the EMR, whereas 84% of patients in our project completed the paper copy of readiness tool. This may suggest that paper documentation is a necessary intermediary step in incorporating such a tool into regular practice.

The importance of patient/parent engagement in the HCT process is the focus of another HCT QI project located in a Federally Qualified Health Center. While similar in population and practice changes, the authors focus on parent and patient perceptions of the importance and confidence in HCT (Lestishock et al., 2021), whereas our project focused on change in practice workflow, provider intervention, and education of patients. Since the end of our project in 2020, Got Transition® has published a QI primer for HCT that describes in detail the process of using QI to implement the steps of transition. This primer is an excellent review of QI principals as it relates to HCT and specifically incorporating Got Transition's six core elements into a practice sustainability (Noonan et al., 2020; White, Schmidt, Shorr, Ilango, Beck, & McManus, 2020).

As a result of this project, distribution of the transition brochure and tool and HCT discussion by PCCs have been incorporated into routine practice. In January 2020 the transition tool was shortened to the 15 items recommended in the final survey.

During the peak COVID pandemic (March to May 2020), the project was put on hold when the focus of in-person visits were newborns and toddlers needing routine vaccinations. Adolescent visits and HCT preparation restarted in the summer/fall of 2020 and are ongoing. Future goals include additional educational material about HCT and the transition brochure to the EMR to be included as part of the after-visit summary; and expanding this project to other pediatric practices in our organization.

Limitations

We sought to have diverse stakeholder representation on our QI project team, but attempts to recruit a patient and parent advocate were unsuccessful and an adult medical provider initially involved later resigned. Both were due to problems with meeting scheduling and availability. Although a balancing measure (i.e., cycle time) was calculated at baseline, we were unable to continue to collect this measure because visit time was impacted by a variety of factors outside our locus of control, including the additional adolescent screeners. This QI project took place in a large urban academic practice serving a low income,

ethnically diverse population. As this was a QI project focusing on a local problem, these results may not be generalizable to other practice settings, although we hope that others may find implementation strategies useful in their own work. Future research could address these limitations by formally testing the brochure and transition tool across multiple practices in different contexts using formal implementation science models to understand contextual factors related to any variations in outcomes.

Implications for practice

Standardized transition education and assessment of gaps of knowledge has been incorporated into routine adolescent HCM visits by using QI techniques, including repeated engagement with and listening to stakeholders, involving all staff and administrators, and letting early adopters share their successful experiences as a model. In addition to this QI project, we are working on consistent use among providers of a medical transition summary in the EMR for youth 18–21, and a workflow for medically complex patients who are aging out of pediatric practice.

Conclusions

Using QI methodology and change concepts can successfully increase PCCs' preparation and assessment of adolescents' HCT readiness by incorporating distribution of transition information, standardizing tools for provider discussion and documentation into the workflow of a busy primary care practice. By formalizing and standardizing the transition readiness process, pediatric providers can include transition education into the adolescent HCM visit

Author contributions

All authors of this manuscript substantially contributed to the conception and design, contributed to the analysis, and interpretation of data, drafted the manuscript, critically revised the manuscript for important intellectual content and agree to be accountable for all aspects of the work.

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