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Implementation of a Portable Medical Summary for Adolescents and Young Adults With Medical Complexity in Transition to Adult Health Care

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ABSTRACT

Background: Adolescents and young adults (AYA) with special health care needs are living into adulthood, as improvements in care increase the likelihood of survival. Fewer than half have the resources needed to transition to adult care (McPheeters et al., 2014). A portable medical summary is a concise document summarizing current medical information about a patient that can be used across healthcare systems as AYA transition to adult care. Though a consensus statement recommending the use of such a summary has existed for over a decade (American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), American College of Physicians-American Society of Internal Medicine (ACP-ASIM), 2002), little progress had been made in the development of a portable medical summary.
Methods: The Institute for Healthcare Improvement (IHI) Model was used to implement a process to provide a portable medical summary to AYAs with medically complex conditions (Institute for Healthcare Improvement, 2017).
Interventions: The tool was developed using the electronic health record and shared with families. Feedback from care providers and families led to modifications to improve its usefulness and feasibility. Implementation of the process was tested for four months.
Results: The number of AYA, ages 16–24, who were being seen for well care or chronic care management visits, and had a portable medical summary initiated, had increased from 0% to 100%.
Conclusions: The use of a PMS that summarizes medical care received in the pediatric system, is one tool that may be used to bridge the gap between pediatric and adult care.

Introduction

Adolescents and young adults (AYA) with special health care needs are surviving childhood-onset chronic disease due to improvements in medical care and treatment options. In the United States, the overall infant mortality rate in 2000 was 6.9 deaths per 1000 live births (Matthews, Menacker, & MacDorman, 2002), and improved to 5.87 per 1000 live births by 2016 (Xu, Murphy, Kochanek, Bastian, & Arias, 2018). It is estimated that more than 750,000 AYA transition to adult care every year in the United States. However, most of these AYA do not have the resources necessary to maintain adequate support and services (McPheeters et al., 2014). Transitioning AYA with medical complexity to adult primary and specialty care is a challenge in the current healthcare macrosystem (American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group [AAP, AAFP, ACP], 2011). As families of AYA with medical complexity prepare to transition from pediatric to adult medical care, it is important to have current healthcare information shared with the new provider to assure continuity and minimize gaps in care (Cohen et al., 2012).

The discussion about transitioning a child who has had frequent contact in the pediatric medical system because of the complexity of their care is often a stressful conversation for families and their care providers (American Academy of Pediatrics et al., 2011). Parents and AYA have reported fear and anxiety when transition from the pediatric to adult care system was discussed (Chesshir, Brown, Byerley, & Ward-Begnoche, 2013). Paramount to the success of transition, is education about the process as well as the provision of tools to assist families and AYA (Betz, Lobo, Nehring, & Bui, 2013). The portable medical summary (PMS) is a document used as a care summary for children with medical complexity, so their care can be continued without disruptions or gaps across systems as they transition to adult care (Wirth & Kuznetsov, 2016). Parents report fatigue when asked to repeat the details of their child's past medical history at healthcare visits. Providing a document that succinctly summarizes the AYA's "story", and key components of their current medical needs, may provide reassurance to the family

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that the needs of their child will continue to be met in the adult health care system. A PMS, created using the electronic health record, is easy to use, retrieves the information in a reliable format, and may guide the adult provider as they initiate care for the young adult with medical complexity.

Problem description

The Complex Care Center (CCC) at a Midwestern, pediatric, quaternary care facility, provides primary care to children and AYA with medical complexity. The center has a formal policy outlining the expectation that AYA will ultimately transition primary care to an adult provider. The policy describes the length of time the clinic will continue to provide primary care as part of a primary care medical home. There is also an office procedure for off-boarding or transferring patients to new providers. Prior to the initiation of this project, there was not a standardized process for informing a new adult care provider about the care needs of the AYA. There was also no standardized transition planning documentation or a summarizing document that could be electronically generated to provide critical information. The risks of transitioning to adult healthcare without a summarizing document are discontinuation of care, worsening chronic conditions, duplicative medical testing, increased use of emergency services and increased risk for death (White & Cooley, 2018). The portable medical summary (PMS) fills this communication gap by providing key information about current medical problems, medications, allergies, surgical history, and immunizations. It includes a brief patient summary that provides a high-level overview of the AYA's current medical “story” as well as documentation of transition planning. This PMS may lead to improved transition outcomes, and increase patient and family satisfaction by providing a summarizing document that families can carry with them.

Available knowledge

A review of the transition literature demonstrated a paucity of information about communication between care providers, and none that evaluated the effectiveness of a portable medical summary (PMS). However, there was endorsement for the use of a transition summary. Lemly, Weitzman, and O'Hare (2013) recommended the use of technology to create a PMS as part of a packet shared with the family and eventually the new provider. Hunt and Davis (2017) advocated for a transition summary to support the AYA and family during the period of transition. They stated a transition summary could be used as a tool that engages the AYA and family in taking ownership of their healthcare. Furthermore, they supported handing the document to the AYA and family as a symbolic gesture that responsibility for care would be shifting to them (Hunt & Davis, 2017).

National organizations supported the need for a PMS. A consensus statement recommending the use of such a summary has existed more than a decade (American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), American College of Physicians-American Society of Internal Medicine (ACP-ASIM), 2002). The Society of Adolescent Medicine (SAM) advocated for care of adults with special health care needs originating in childhood to receive care in an adult setting with adult standards of care and continued collaboration between pediatric and adult providers (Society of Adolescent Medicine [SAM], 2003). The 2011 Clinical Report, published by the American Academy of Pediatrics, stated that a PMS is necessary for a new provider to assume care of a child with medical complexity. The summary should contain pertinent medical and social information (American Academy of Pediatrics et al., 2011). Recommendations to have a PMS were found in the Got Transition “Six Core Elements of Health Care Transition”, specifically Element 5, Transfer of Care (National Alliance to Advance Adolescent Health, 2014). This element suggested the maintenance of a PMS and emergency care plan as part of the transition process. Davidson, Doyle, and Silver (2015) discussed the importance of including a PMS as part of the transition process. Finally, the Society of Pediatric Nurses position statement on transition to adult care (2016) reported the lack of a PMS as a barrier to successful transition to adult care.

Rationale

The Chronic Care Model, developed by Dr. Edward Wagner (Wagner, 1998), was used as a framework for this project. In this model, six elements guide care provided in the primary care medical home. These include community resources and policies, health care organization, self-management support, delivery system design, decision support, and clinical information systems. The authors of this model predicted improvements in care with informed and engaged patients and families who interact with high performing care teams (Bodenheimer, Wagner, & Grumback, 2002). Dr. Wagner argued that improved chronic disease management is beneficial to the population of those with chronic illness (Wagner, 1998).

Application of this model can be used in the medical home when discussing and planning for transition to adult care. The elements of the Chronic Care Model include self-management support, delivery system design, and clinical information systems. Using the electronic health record to create a summarizing document that can be used across systems of care is well aligned with this model. Standardization of the process to create this summary assures each AYA with medical complexity receives services necessary to assist in this transition. Additionally, the use of the PMS during transition to adult care, may increase family satisfaction by decreasing their fears that the new provider does not have the information necessary to adequately care for the young adult (White & Cooley, 2018).

Specific aims

The specific aims for this quality improvement project were:

1. Implement a process to increase the weekly completion of a portable medical summary (PMS) for use in transition to adult care in adolescents and young adults (AYA), ages 16–24, who have Tier 2 and 3 medical complexity (Simon et al., 2014), and are seen for well-check-up and chronic care management visits at two CCHMC locations from September 1 through December 31, 2017, by 90% of eligible patients.
2. Assess feasibility of the process by using balancing measures to evaluate whether other problems were created within the system with the initiation of the PMS.

a. Analyze time needed for completion of the tool, and its potential impact on provider workload and clinic flow.
b. Analyze length of visit, in minutes, to see if the creation of the PMS increased the length of the visit.

Methods

Context

Preparing AYA with chronic, complex medical conditions to transition to adult care, aligned with goals set by the CCC to develop strategies to meet the qualifications for certification as a Primary Care Medical Home (PCMH) by the National Committee for Quality Assurance (NCQA). The documentation of transition planning, including the completion of a PMS, meets the PCMH standards and guidelines for one of the optional elements of this certification, which is to show evidence of a transition plan in the medical record (National Center for Quality Assurance [NCQA], 2017).

Interventions

The Institute for Healthcare Improvement (IHI) model has been used extensively to plan, implement and evaluate plans for systemic change (Langley et al., 2009). A Key Driver Diagram (See Fig. 1) was used to guide the work of the quality improvement project and move it forward. A SMART aim was developed, key drivers were identified, and interventions established that would move the project towards its goal.

In the pre-assessment phase of this project, the tool was tested to determine the reliability of retrieval of patient information from the electronic health record (EHR) using "smart phrases" to efficiently capture content for a prototype transition summary tool. Additionally, families who requested a summary of their child's medical history for use when relocating or traveling, were given a summary created using this new process. These families provided feedback, and their suggestions led to a refinement of the tool. For this quality improvement project, the refined version of this tool was evaluated in the clinical setting, and the process was spread to the other providers in the clinic using Plan-Do-Study Act (PDSA) cycles. Oversight of the project was provided by an interprofessional team which included a social worker, two social worker care managers, two nurse care managers, a nurse clinical director, a business manager and the project leader, who is an advanced practice registered nurse.

Study of the intervention

Improvement of the process was demonstrated by measuring the percent increase in weekly completion rates of portable medical summaries for AYA who met inclusion criteria. The numerator equaled the number of medical summaries completed, with the denominator representing the number of eligible AYA seen in one week. Because the tool was novel in the mesosystem, the baseline was established as zero. Retrospective chart review was used to predict the number of AYA who would have met inclusion criteria in the five-months prior to project implementation so that weekly volume could be anticipated. This information was used to assure the team that implementation of the process was unlikely to significantly impact clinic flow.

As part of the usual preparation for clinic visits, the electronic health record for each scheduled patient was thoroughly reviewed by the provider, prior to patient arrival. Additionally, a pre-clinic huddle was used to remind the team when an AYA eligible for a PMS would be coming for a clinic visit. Once the visit was completed, the clinic nurse provided an explanation of the PMS when it was handed to the family. If the PMS was not ready by the end of the visit, the nurse informed the family that the PMS would be mailed to them.

The providers were given an evaluation tool by the project leader after each portable medical summary (PMS) was completed. They were asked to rank its feasibility and usefulness using a Likert scale, identify missing information, and make recommendations for changes to the tool. They were also asked to document the length of time (measured in minutes) to complete the PMS.

Family feedback was collected via telephone call by the project leader after each visit to determine whether the PMS met the needs of the family, and ensure the "story" (brief patient summary) of the AYA was accurate. The family was informed of the upcoming call by the clinic nurse at the end of the visit. The project leader attempted to contact the family three times. If no return calls were received, there was no further attempt to reach the family. If a return call was received, attempts to reach the family continued until contact was made. A questionnaire was read to the family during the telephone call and responses were

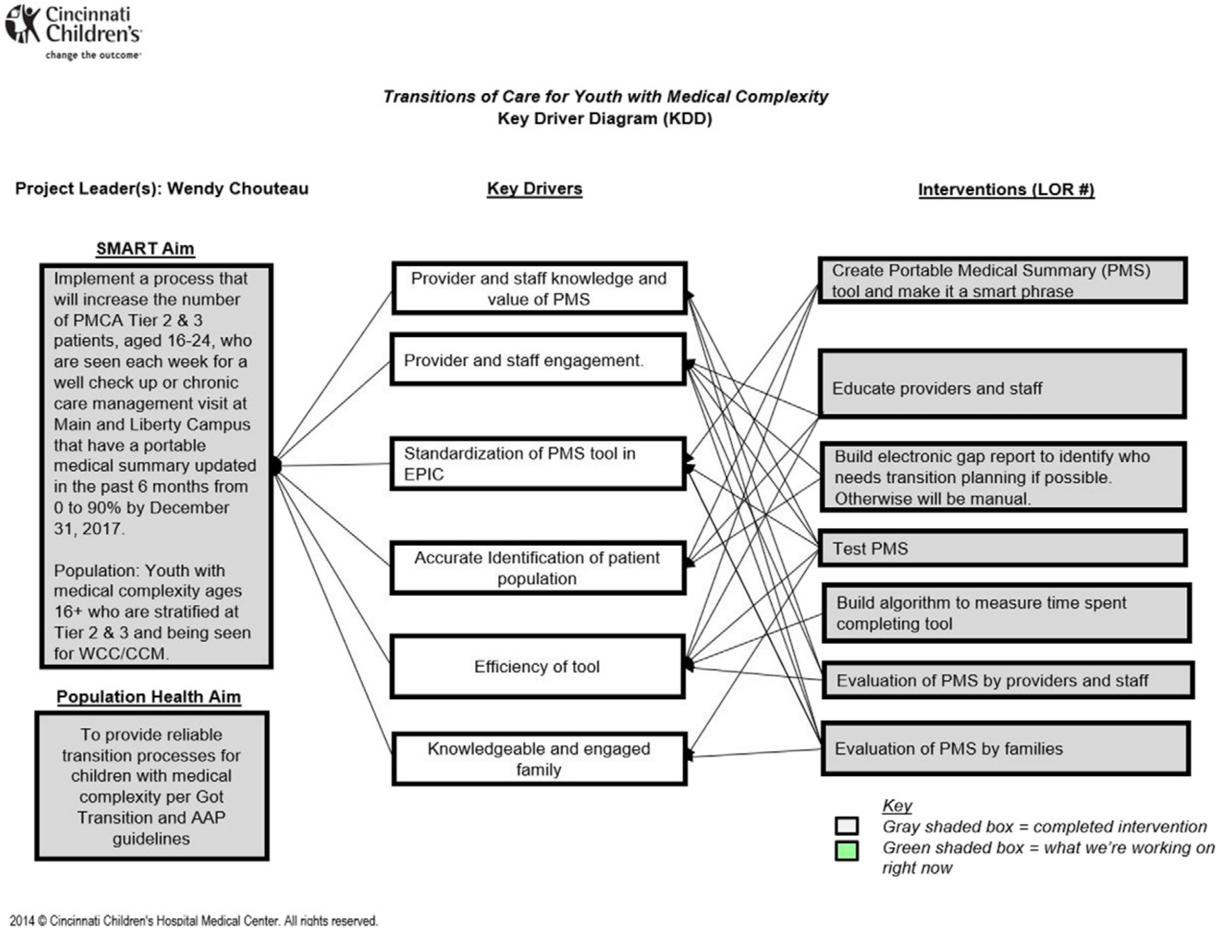

Fig. 1. Key driver diagram.

recorded by the project leader. Modifications to the brief summary were made based on their comments.

Measures

The first aim of this quality improvement project was to initiate a process that would increase the rate of completion of a portable medical summary (PMS) for eligible AYA. A run chart (See Fig. 2) was utilized to demonstrate completion rates and to illustrate whether the data showed a shift or trend by observing changes over time after the study was initiated. Analysis of each PDSA cycle provided key information about the intervention to determine if there was improvement. Results of the PDSA cycles were discussed with the interprofessional work team in biweekly meetings. The team also gave recommendations about the transition planning documentation and the elements of the portable medical summary (PMS) to be included. Modifications to the tool were informed by feedback from providers, families and the work team. Any change to the PMS initiated a new PDSA cycle which was annotated on the run chart.

Balancing measures were used to evaluate whether there were other problems created within the system after initiation of the PMS. The project leader and work team recognized adoption of the process could impact provider workload as well as affect clinic flow. Several measures were evaluated. Data were analyzed to compare the monthly average length of visits before and after the intervention. Additionally, data were analyzed from provider feedback which included time spent completing the PMS, feasibility and usefulness of the PMS.

Analyses

Analyses of the project aims were performed by evaluating the effectiveness of the process measures. There were six PDSA cycles during the study period. At the initiation of the project, completion of the tool required the provider to copy and paste five EHR elements: the brief summary, the transition plan, a review of systems, the physical examination, and the assessment and plan for the visit. Feedback obtained in discussion with the work team and physician providers was that the PMS was essentially the same as the progress note for the clinic visit and it was lengthy.

During PDSA 2, further changes were made to the PMS and transition planning documentation per recommendations by the work team. If the AYA was not connected with developmental disability (DD) services, the social worker took this opportunity to ensure that a relationship was established between the AYA's family and the county DD office. The project leader continued to evaluate and discuss important components of the PMS with the health care team. While attending the 18th Annual Baylor Transition from Pediatric to Adult-based Care Conference, in Houston, Texas, the project leader had informal conversations with national experts. It was during these discussions that the project leader learned immunizations were also an important component of the PMS. This was corroborated by a discussion with an adult care provider at a local medical institution. Therefore, an electronic phrase that automatically pulled the list of immunizations was added to the tool; this initiated PDSA 3.

During PDSA 3, the process was spread to an additional provider and a shift in the data was observed. Using information from the provider feedback form, modifications were made to the tool (see Table 1) which initiated PDSA 4.

During PDSA 4, the run chart demonstrated continued adoption of the process and 100% completion rate was achieved with the spread of the process to the other physicians in the practice. Provider feedback recommended removal of the comprehensive review of systems, suggesting this information was better suited for a transition transfer letter. Removal of this information substantially shortened the PMS. The

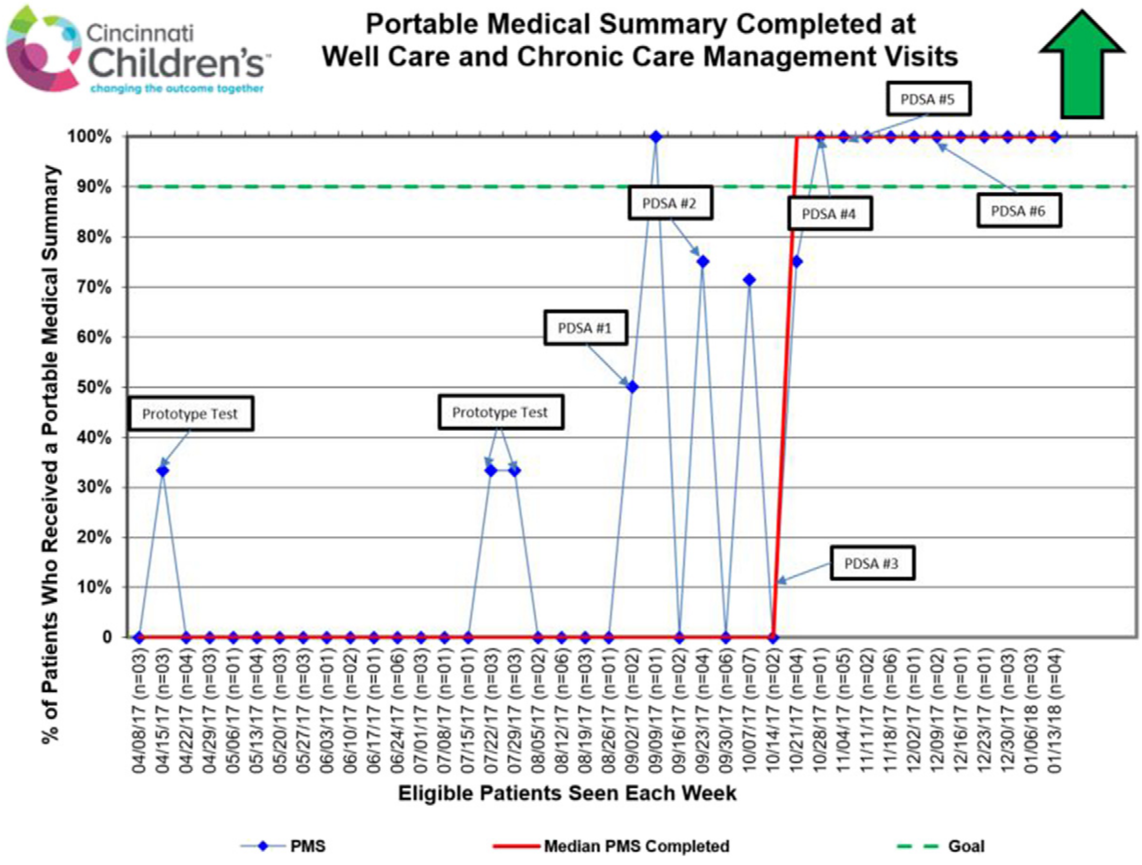

Fig. 2. Portable medical summary run chart.

Table 1
Portable medical summary project PDSA cycles.

PDSA 1	Initiation of Portable Medical Summary (PMS) smart phrase in a letter template. Contained brief, descriptive summary, current medical problems, comprehensive review of systems, past surgical history, transition plan, medications and allergies, current vital signs, current physical examination, list of names of primary and specialty care team, plan for visit.
PDSA 2	Dropped assessment and plan from PMS. Transition plan modified: Information about guardianship and name of county developmental disability (DD) office contact was added.
PDSA 3	Added immunizations to PMS. Tool spread to one physician provider.
PDSA 4	Moved examination closer to vital signs in PMS. Tool spread to other two physicians.
PDSA 5	Removed review of systems from PMS; Social workers complete PMS and transition plan documentation with provider input.
PDSA 6	Physical examination removed from PMS.

providers also suggested social workers assume responsibility for initiating the PMS process, which was agreed collaboratively by the social work team. The social workers requested providers continue to develop the brief patient summary and discuss key parts of the transition plan with families. With these modifications, PDSA 5 began.

In the final version of the PMS, it was determined the physical examination was unnecessary. If time allowed, the PMS was completed during the visit, but if not, it was finished after the visit, and mailed to the family. These changes initiated PDSA 6. Completion rates for the PMS remained stable for the duration of the four-month study period.

Ethical considerations

This quality improvement project was reviewed by the Cincinnati Children's Hospital and Xavier University Institutional Review Boards (IRB) prior to implementation of the project. It did not meet the regulatory definition of research involving human participants.

It is the right and privilege for all youth and young adults (AYA) to receive age appropriate care, but it is also the right and privilege of those with severe neurocognitive deficits to receive developmentally appropriate care (Society of Pediatric Nurses [SPN], 2016a, 2016b). There are ongoing concerns by pediatric clinicians that lack of understanding by adult care providers about the developmental needs of those with neurocognitive conditions such as cerebral palsy, autism, and severe developmental delay may decrease successful transitions. The pediatric health care system has adaptive care plans for children and AYA with severe behavioral issues. Adult care sites do not have these accommodations. Lack of communication and coordination between pediatric and adult practices has been cited as a barrier to successful transition. It is the ethical responsibility of pediatric and adult practices to establish relationships and to build bridges to facilitate safe and appropriate transfer of care. Without such collaboration, the risk to these AYA is poor outcomes, the potential for a return to the pediatric system, increased hospitalizations, and ultimately, increased costs of care (White & Cooley, 2018).

Results

During the project period, 49 patients met inclusion criteria. One patient had Tier 2 medical complexity and 48 had Tier 3 medical complexity (Simon et al., 2014). Because the project leader tested the tool initially, AYA who met criteria and were being seen by another provider, did not receive a portable medical summary (PMS) at their visit. A PMS was completed for 35 patients. Of those, 25 were completed by the project leader. A PMS was not completed if the condition of the patient did not warrant a transition discussion. For example, one patient had a life-threatening condition, so discussion about transition during this sensitive time did not occur. Additionally, if a patient was scheduled to see a provider who was not yet participating in the quality improvement project, a PMS was not completed.

It is important to look at balancing measures during any quality improvement project to determine whether the initiated process affected other parts of the system (Provost & Murray, 2011). The project team identified challenges in implementing a new process in a busy primary care practice and took steps to mitigate them. Providers were asked to rank the PMS for feasibility and usefulness using a Likert Scale from 1 to 5, with 1 equaling not feasible or useful and 5 equaling extremely feasible or useful. The physician providers did report the tool could be useful but did not think they should be completing it. There was a need for the provider, however, to complete portions of the transition planning discussion, including recommendations for adult primary care providers, informing the need for clinical accommodations for the patients and documenting discussions about advanced care planning.

Providers who completed the PMS were also asked to report how much time (measured in minutes) was spent completing the document. Total times were averaged and reported. It was anticipated the time to complete the summary would decrease, as familiarity with the document was gained. The project leader ($n = 25$ PMS completions) decreased her average time to complete the summary from 35 min to 5 min by the time the project ended. Another provider ($n = 5$ PMS completions) saw an average decrease in time from 30 min to 10 min. A third provider ($n = 3$ PMS completions) reported that the average completion time of the summary took 60 min. The fourth provider ($n = 1$ PMS completion) reported it took 10 min to complete.

The second balancing measure was to evaluate whether the process impacted the length of the clinic visit. Average length of visit was calculated for AYA who met inclusion criteria before and after implementation of the process to determine whether the length of visit increased. A two-sample *T*-Test demonstrated no statistically significant difference in the average length of clinic stay after study initiation, $p = .650$.

The project leader telephoned the family after the PMS was completed and handed or mailed it to the family. Of the 35 AYA who received a PMS, feedback was obtained from 28 of the families. A feedback questionnaire was administered to families which asked them to rank the usefulness of the tool. A Likert scale was used to rank the tool from 1 to 5, with 1 equaling not useful and 5 equaling extremely useful. Sixty-eight percent of the respondents reported the PMS was extremely useful, while 32% found it very useful.

Parents were also asked if the PMS increased their confidence about transitioning to adult primary care. Ninety-three percent of families reported increased confidence with transitioning to adult primary care after the PMS was made available. Seven percent stated that they were not at all confident transitioning their child with a medically complex condition to adult primary care.

Discussion

Summary

The primary objective of this project was to develop a process that would increase the number of portable medical summaries (PMS) created for AYA with medical complexity when seen for well care and chronic care management clinic visits, by using a smart phrase in the electronic health record (EHR) to capture data for the summary. Using rapid cycle changes, this quality improvement project established a standardized approach to the discussion about transition from pediatric to adult medical care for patients in the Complex Care Center outpatient clinic, as well as produced a summarizing document to be utilized across systems of care.

There were several key facilitators to the success of this quality improvement project. First, was the engagement of the CCC work team and the clinic team. The manual gap report, created by the project leader, identified AYAs who were eligible for a PMS. The support of the medical director, and the use of the daily huddle to identify eligible AYA, helped the team recognize the need to complete the transition planning discussion and the PMS. In summary, using PDSA cycles, eligible AYA's families reliably received a PMS at well care and chronic care management visits.

Interpretation

The CCC work team was engaged in the creation and maintenance of the process to establish a standardized approach to the transition planning discussions and ensure its stability. The run chart for the project, used to graphically display data points, demonstrated improvements in the process over time with its adoption by the healthcare team.

Provider satisfaction with the tool varied. One provider verbally stated the document was not necessary until the AYA was ready for transfer. The other two providers stated they saw it as a valuable tool. By the end of the project, all providers continued to work with the social workers to use the smart phrase to develop the PMS and share it with families.

Family feedback was overall favorable. During the study period, families were encouraged to review the document and provide feedback so that modifications could be made to the problem list and the brief, descriptive patient summary. Many families reported they were glad to have the information about their child in one document. They reported using it for school and day camps, and some families verbally reported they also shared it with nursing agencies providing care to the patient in the community setting.

Limitations

The PMS did not contain all the information that would be important when AYA transfer care to an adult provider because of limitations in the electronic health record (EHR). Many of the Tier 3 (Simon et al., 2014) AYA had chronic medical conditions that required medical equipment to be sent and maintained in the home. Specifically, there was no way to electronically track durable medical equipment (DME) and supplies needed for the care of the AYA in the EHR. Also, the EHR did not include a discrete electronic field that contained the name of the DME company or nursing agency to which orders should be sent if the plan of care changed during a clinic visit.

The creation of the patient summary requires careful thought so the “story” of the AYA is adequately captured. There were times when completion of the PMS during a clinic session was not feasible because the brief patient summary had not yet been created. If the summary was not ready by the end of the visit, the PMS was completed after the visit and mailed to the family.

Bias in the completion rates may have existed since the project leader completed most of the portable medical summaries during the study period. However, the project leader carried the largest patient panel in the practice which contributed to this difference. Continued analysis of the completion rates after the study period will help determine whether the process was sustained. Additionally, the project did not examine the impact of the process on the satisfaction of the social workers or their time spent completing the summary.

Conclusions

The use of a PMS that summarizes medical care received in the pediatric system, is one tool that may be used to bridge the gap between pediatric and adult care. AYA with complex medical needs are inherently at risk for poor health outcomes when transitioning from pediatric to adult care. As a planning tool, the PMS is one way to engage families and a way to develop and standardize the documentation of the care needs of these vulnerable youth. Preparation of the AYA and family, using a planned, coordinated approach to transition, provides support to the family and reassurance that the AYA's health is important. Research is needed to understand and evaluate the experiences of families of AYA with medical complexity as they transition to an adult primary care provider. Follow up studies are needed to evaluate whether their beliefs change following their AYA's transition to adult primary care.

Interprofessional collaboration among the healthcare team is key to the success of any quality improvement project (Naylor et al., 2011). The team, when challenged to define solutions, provides a wide lens for solving problems. Using technology as a solution has been mandated by the American Recovery and Reinvestment Act (ARRA, 2009). The use of Smart technology has generated consumer demand for access to their health record (Hickey & Brosnan, 2017). Creating the PMS, utilizing tools available in the EHR, standardized the process and made it efficient.

Ultimately, there is a shared responsibility for safe, quality care for AYA with medical complexity as they transition to adult primary care. Ensuring safe transfer assures continuity of care into the adult health care system. Developing professional relationships with adult providers to deliver care handoffs may keep AYA with medical complexity safe and ensure ongoing appropriate care. White and Cooley (2018) recommend the development of educational interventions for both pediatric and adult care providers to fill knowledge deficits and increase comfort in caring for the young adult with a medically complex condition. Greenlee et al. (2017) call for internal medicine providers to be more aware of the needs of the AYA who are transitioning to adult care. The American College of Physicians has developed toolkits to help educate clinicians (American College of Physicians, 2016). Future research is needed to understand the adult primary care providers' experiences in providing care to this population.

The use of a PMS should not be limited to the primary care setting. The document could be used in other settings, including specialty clinics, in which AYA with single chronic disease entities are seen, such as those with diabetes, rheumatoid arthritis or cystic fibrosis. A PMS could also be shared with home care agencies to help facilitate the development of the patients' nursing plan of care. Finally, it could be shared with schools and community agencies, and used as an emergency care plan when AYA are not receiving care from their primary caregivers.

It is important to approach transition to adult care holistically, using models of care that prepare the AYA and family to move from pediatric to adult health care. Developing algorithms for care that include transition preparation, readiness assessments, and processes that ensure the AYA continues to receive adequate care, without lapses that could cause unnecessary complications, is key. Following the AYA longitudinally, using a care management model to assure continued coordination of care with primary and specialty services, would be ideal. Future studies evaluating the health outcomes of AYA with medical complexity who transfer to adult primary care may identify and alleviate gaps in this area.

CRediT authorship contribution statement

Wendy A. Chouteau: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - original draft, Writing - review & editing, Visualization, Supervision, Project administration. **Susan R. Allen:** Methodology, Validation, Writing - review & editing, Supervision.

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