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Pediatric to adult primary care transition for medically complex youth: A tale of learning from challenges experienced implementing a pilot project during COVID-19

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ABSTRACT

Purpose: The aim of our article is to describe our learning based on challenges encountered implementing two related pediatric to adult primary care transition pilots for medically complex adolescents and young adults as part of the Children with Medical Complexity Collaborative for Improvement and Innovation Network.

Design: We undertook two sequential pilot projects. The first focused on supporting the transfer stage for an older group of medically complex young adults to facilitate their establishment with an adult primary care provider. Based on our learning from barriers encountered, and setting constraints due to COVID-19, we developed and implemented a second project to engage pediatric primary care providers in initiating and documenting transition preparation discussions for a younger group of medically complex youth. A multi-disciplinary Implementation Team guided each phase's implementation.

Results: We did not achieve our objective in the first pilot, partly due to provider reluctance. Providers perceived the patient was not ready, reported that the patient was experiencing active health problems, or wanted to keep the patient on their panel. We partially achieved the second pilot's objective; three-quarters of identified patients completed their appointments, and electronic health record documentation suggests that providers initiated transition discussions with more than half of those patients.

Conclusions: Pediatric primary care has an important role in supporting health care transition for medically complex youth. Our findings suggest that pediatric primary care providers require time, connection to adult PCPs, and educational support to realize this role.

Practice implications: To provide comprehensive transition services for medically complex patients, pediatric primary care will need to develop relationships with adult primary care providers, make available training about transition preparation for its providers, and support patients and families in locating adult primary care providers who are accepting new patients.

1. Introduction

Children with medical complexity (CMC) are a unique population, defined as those who experience “multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care needs or utilization, and often the need for or use of medical technology.”[1] Estimates for children with medical complexity range from $<$ 1–6% of the pediatric population.[2–4]

Abbreviations: AYAMC, Adolescents and young adults with medical complexity; CMC, Children with medical complexity; CYSHCN, Children and youth with special health care needs; EHR, Electronic health record; HCT, Health care transition; IT, Implementation team; OCCYSHN, Oregon Center for Children and Youth with Special Health Needs; PCP, Primary care provider.

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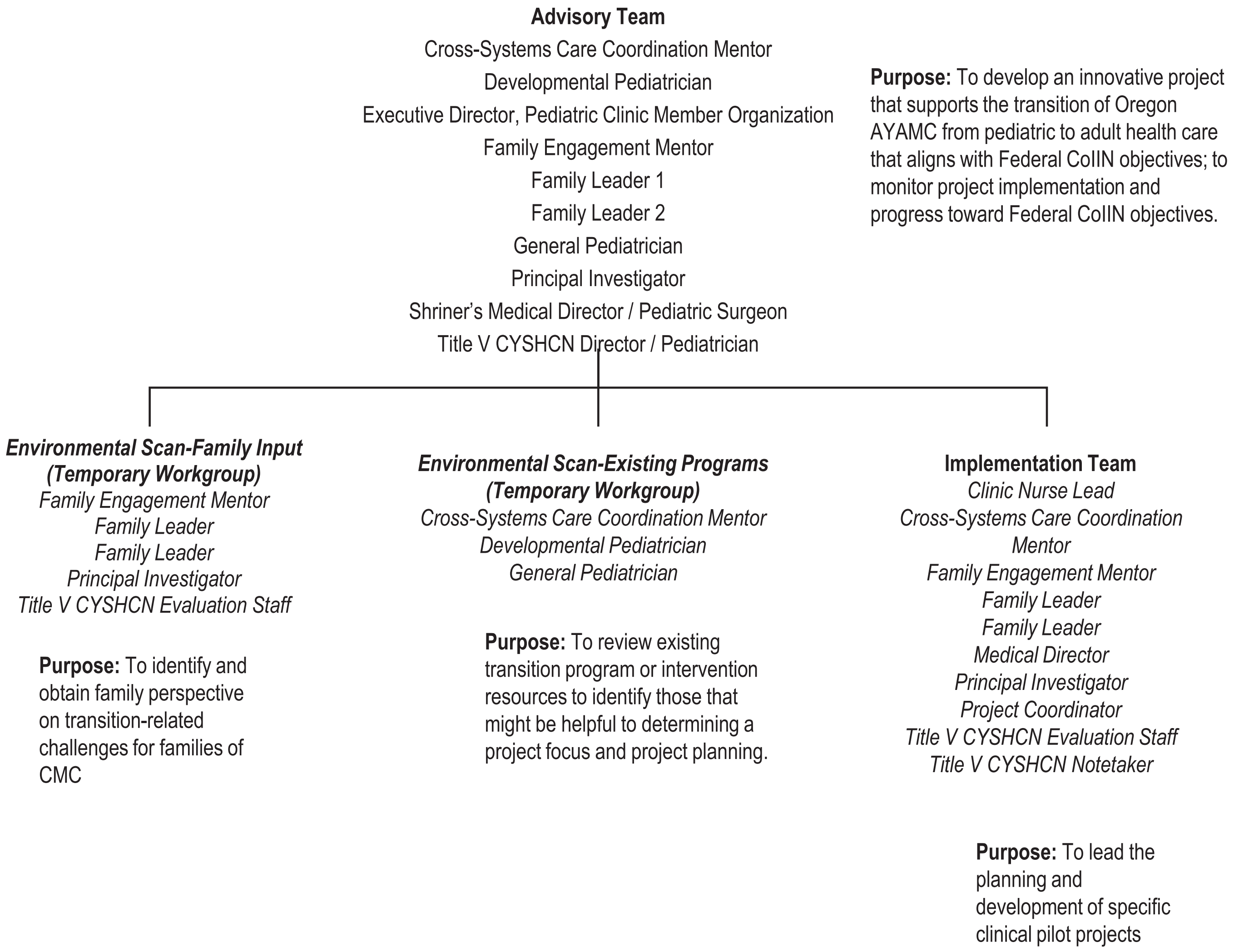
Transitioning to adult care is especially difficult and complicated for adolescents and young adults with medical complexity (AYAMC),[5] yet they are unlikely to receive transition preparation services.[6,7] Given the multiple dimensions of their complexity, AYAMC and their families need intentional and directed transition preparation and planning.[8,9]

From 2017 through 2022, the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) funded Boston University's Center for Innovation in Social Work and Health (BU) to lead a ten-state learning community focused on CMC: the CMC Collaborative for Improvement and Innovation Network (CoIIN). The Bureau uses the CoIIN model to test innovative approaches for addressing issues affecting maternal and child health populations (e.g., home visiting, infant mortality, school-based health centers). The CMC CoIIN focused on testing coordinated care delivery strategies and associated payment methods for CMC. The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), Oregon's Title V CYSHCN agency, led Oregon's CoIIN team, and aligned our team's focus with one of Oregon's CYSHCN priorities: transition to adult health care.

AYAMC are a population of children and youth with special health care needs (CYSHCN)[1]. Consistent with trends observed elsewhere,[10] Oregon CYSHCN typically did not receive preparation services for transition from pediatric to adult health care at the time of our project's development.[10,11] Our team interviewed families of young adults, between the ages of 18 through 22 years living in Oregon and Southwest Washington, with medical complexity to better understand whether the young adults had transferred to adult health care, and if so, whether the families' experienced structured transition, and to obtain recommendations for improvements to clinical transition care.[12] Families described difficult preparation, transfer, and integration experiences that included inadequate transition guidance, families having to take the lead with transfer planning, difficulty finding adult providers and working in adult health care to obtain care for their young adult, and negative consequences of poorly supported transition.[12]

BU's grant leadership encouraged CoIIN teams to use quality improvement tools, like root cause analyses, to inform their strategy development. Results of our family interviews and other information sources informed our root cause analysis, including creation of the following problem statement, "young adults with medical complexity and their families are not adequately prepared for, or supported in, the transition from pediatric to adult health care."[13] This statement served as a touchstone while developing our strategy. Additionally, after completing our root cause analysis, our Advisory Team (Fig. 1) committed to focusing Oregon's CoIIN work on health care system improvements to transition care, not on trying to change AYAMC and families. This perspective served as a guiding principle for developing our strategy.

Primary care providers have an essential role in supporting the transition process for AYAMC.[14] Standards of care suggest that beginning care transfer by first establishing with an adult primary care provider will aid CYSHCN, AYAMC, and their families with subsequent



Purpose: To develop an innovative project that supports the transition of Oregon AYAMC from pediatric to adult health care that aligns with Federal CoIIN objectives; to monitor project implementation and progress toward Federal CoIIN objectives.

Purpose: To identify and obtain family perspective on transition-related challenges for families of CMC

Purpose: To review existing transition program or intervention resources to identify those that might be helpful to determining a project focus and project planning.

Purpose: To lead the planning and development of specific clinical pilot projects

Fig. 1. Oregon CMC CoIIN Structure.

transfers to adult care specialists given the myriad providers and support services used by AYAMC.[15] Yet, examples of implementation of the primary care transition process for AYAMC are lacking.[16–18] OCCYSHN partnered with Doernbecher Children's Hospital's General Pediatric and Adolescent Health Clinic located at Oregon Health & Science University to develop and implement a clinical quality improvement project supporting AYAMC transition to adult health care. At the time of our intervention, the first author was implementing a structured care management program focusing on pediatric patients with medical complexity. This was a multidisciplinary collaboration with strong nursing leadership focused on determining how to best support the clinic's most complex patients during periods of heightened need. Care management program staff identified transition to adult primary care as one period of heightened need. Therefore, our Oregon team centered our strategy on assisting AYAMC and their families in transition from pediatric to adult *primary* health care.

The aim of our article is to describe our learning from implementing two related primary care transition pilots as part of the CMC CoIIN learning community. Initially, we focused on transfer preparation for an older group of AYAMC (>20 years). The desired outcome was for AYAMC to establish care with an adult primary care provider. Overall, our team did not achieve this goal. After reviewing the barriers encountered during our first pilot, including the COVID-19 pandemic, our team revised our project to focus on supporting providers to engage in transition preparation with a younger group of AYAMC (13–15 years). The desired outcome was for participating pediatric primary care providers to initiate and document transition discussions with AYAMC in the patient's electronic health record. We partially achieved this outcome, and our learning can inform other efforts to prepare AYAMC and their families for transition.

2. Methods

2.1. Timeline and setting

We conducted two pilot projects over a two-year period (2019–2021), much of which coincided with the COVID-19 pandemic. We implemented both pilots in an academic general pediatrics clinic, located in a 154-bed children's hospital. This children's hospital is located in a metropolitan area, in the western United States, where approximately 12 faculty general pediatricians and 30 residents deliver pediatric primary care.

The organizational structure for Oregon's CoIIN team is shown in Fig. 1. For the development of our pilot projects, we established a 10-member Implementation Team (IT) composed of Family Leaders, staff from our state's Title V CYSHCN agency, and staff from the academic general pediatrics clinic. Per CMC CoIIN grant funding requirement, OCCYSHN contracted with two mothers of AYAMC to work specifically on this project. Neither parent had previous experience serving on health care quality improvement teams. The IT met on a biweekly basis and was responsible for development of our clinical pilot projects and oversight of their implementation. An Advisory Team determined overall project focus and monitored implementation. The Institutional Review Board approved our pilot projects.

2.2. Population

We focused on the clinic's population of AYAMC. We operationalized medical complexity as the Complex Chronic Disease category of the Pediatric Medical Complexity Algorithm.[19] The algorithm assigns patients to this category if analysis of administrative claims data shows that patients experience (1) ≥ 1 claims for a progressive condition that is associated with deteriorating health with a decreased life expectancy in adulthood, or (2) ≥ 1 claims for a progressive or metastatic malignancy (ies) that affect life function (excluding those in remission for >5 years), or (3) ≥ 2 claims per body system for 2 different body systems during the measurement period, or (4) continuous dependence on technology for at least 6 months.[14] We used this approach because it is integrated into the clinic's Electronic Health Record (EHR) and aligned with related state-level efforts to identify and support medically complex children.[20] Patients who met complexity and age (described further in each pilot) criteria were included.

2.3. Pilot #1: nurse-led transfer preparation

2.3.1. Objective and eligibility

The objective of this pilot was for AYAMC to establish care with an adult primary care provider through implementation of a nurse-led educational intervention to prepare AYAMC to transfer to an adult PCP.[14] This phase took place over an approximately 6-month period from September 2019 to February 2020, and was disrupted by the closure of clinics during the COVID-19 pandemic.

Eligible patients were > 20 years. Our institution lacked a transition policy that specified the age, or age range, in which an AYAMC would transfer to adult PCP. Therefore, we used an age range recommended by clinic PCPs, and expected that providers of AYAMC in this age range would see the benefit of their patient beginning transfer preparation and want our team to approach their eligible patients.

2.3.2. Process

The IT created education content and an associated patient workbook (available upon request) that focused on three topics (1) understanding of the young adult's unique medical conditions, medications, and care team; (2) understanding the role of a medical home and its value in caring for AYAMC; and (3) identification of key attributes for a well-matched adult PCP. We included the second topic as part of building knowledge about the adult model of health care and navigation of the health care system.[5] The third topic also included working with patients to schedule an appointment with the adult PCP. The patient workbook contained an overview and timeline of the project, a welcome letter from Family Leaders that explained the importance of transfer preparation, a health passport template, and other resources to support the transfer process across the engagement period. We determined that nurses would cover the content with patients during three appointments, over the course of the year, and tailor content to each patient's unique health needs. Nurses could go through the content with patients or caregivers either in person or by phone in conjunction with a scheduled health care visit or as a separate visit. We assumed HCT had not been introduced to these patients, and given the condensed timeframe of transfer preparation, we theorized that dedicated effort towards understanding these topics would allow patients and families to improve their health care navigation skills and ability to identify qualities of an ideal adult PCP while not placing undue burden on AYAMC and their families. A schedule of routine outreach and specific goals for each outreach were developed in collaboration with a clinic-based nurse leader. Five nurses worked in the clinic at the time of this project, and all were trained in guiding patients and families through this process.

The clinical members of our IT collaborated with the clinic medical director to ensure that there was leadership buy-in for the project, and then met with PCPs to explain the project. We ran EHR reports on a weekly basis to identify eligible patients who had an upcoming routine appointment with their PCP. We emailed the PCP to ask if the patient might be ready to transfer to adult primary care in the coming 12-month period. If the PCP agreed, a nurse would meet with the patient and/or family at the upcoming provider appointment to explain the project. If they expressed interest after this initial meeting, the nurse consented them into the project and gave them a workbook. The nurse also attempted to schedule follow-up telephone appointments focused on delivery of educational materials. If they were not ready to schedule this appointment, the nurse called the family approximately three to five weeks following the clinic appointment. For families who were difficult to reach by phone, nurses reached out via the EHR's patient portal and attempted to meet the patients when they otherwise presented to the clinic for care.

2.3.3. Assessment

We tracked the number of patients that met eligibility criteria, the number whose PCP we approached, and whether the PCP permitted us to contact the patient. We planned to record the educational topics discussed with each patient during meetings with nurses, and the number of patients who established with an adult PCP. After three weeks of implementation, however, we noticed that our clinic's PCPs frequently declined our team approaching their patients, so we began asking providers for their reasons for opting out. After completion of this phase, we administered an anonymous seven-item survey (available upon request) to each of the five participating nurses. BU CoIIN leadership asked each state team to collect data that could describe unintended consequences of their strategy's implementation. Our nurse survey's purpose was to learn about nurse experience, and any unintended consequences from pilot implementation. Questions asked nurses about the intervention's effect on their workload, its effect on their relationships with patients/families, their perspective on family engagement, and their general experiences with its implementation. Our team's medical director and lead clinic nurse regularly conversed with the nurses about implementation, and shared points from these discussions and her implementation experience during IT meetings (e.g., provider reasons for opting out, families having limited time to talk during nurse-initiated phonecalls, families being ready to leave after meeting with the provider). During each IT and Advisory Team meeting, an OCCYSHN team member took notes, which we then shared with each of the respective teams. We also used the notes to describe our pilot's implementation.

2.4. Pilot #2: provider engagement in transition preparation

The hospital halted clinical research, which included our project, in March 2020 due to the COVID-19 pandemic. From March until October, 2020, when the hospital allowed clinical research to resume, our team conceptualized a second pilot project focused on pediatric PCPs.

2.4.1. Objectives and eligibility

The objective of this pilot was for participating pediatric primary care providers to have an initial transition discussion with AYAMC patients and document the discussion in the patient's EHR. This phase took place over approximately five months (October 2020-February 2021). Eligible patients included AYAMC ages 13–15 years. We chose this age range because it closely aligns with standards of practice for initiating conversations with adolescents[5] and preparing for Oregon's medicolegal changes that begin at 15 years old yet addressed provider concerns that talking about HCT with 12 year olds is too early.

2.4.2. Process

Our IT designed a second intervention, consisting of several supports intended to address barriers encountered during our first pilot. We recruited three pediatric PCPs to participate with the intention of building physician champions before expanding the intervention clinic-wide. The PCPs would be supported by one clinic nurse. We created a handout to describe the medicolegal changes that begin at age 15 in Oregon, which entailed review by our hospital's legal team. We theorized that this tool would help ease PCPs into the discussion of transition. We created an electronic health record (EHR) smart-phrase, with discussion topic options, to support the discussion and its documentation in the patient chart and in the after-visit summary (available upon request). The smart-phrase provided options for additional transition-relevant topics (e.g., reviewing medical conditions, medications, side effects, obtaining refills, scheduling appointments[26]) and goal setting support. We sought to extend patient appointment lengths to ensure PCPs had time to discuss HCT.

In addition, our clinical team members led the IT in developing a 45-minute provider training. We tailored the content to Got Transition's age-specific recommendations and Oregon and clinic specific needs. The training encompassed foundational transition concepts (e.g., three stages of the transition process[26]), Oregon family experiences with transferring providers,[12] examples of HCT topics to discuss with 13–15 year olds (including the medicolegal changes that occur during adolescence), and the clinical workflow for initiating HCT discussions (including the smart phrase) composed our content. We scheduled the training at a time convenient for the three pediatric PCPs. Our team's medical director provided 30 minutes of content and, with our principal investigator, facilitated 15 minutes of discussion.

We identified patients via two mechanisms. First, the clinic nurse reviewed upcoming appointments to identify patients ages 13–15 years with medical complexity. The nurse added the words "transition discussion" to the visit reason. If possible, the nurse extended the appointment length. Second, we used an EHR-based report to proactively outreach to eligible patients overdue for a wellness visit and encourage scheduling an appointment. In these cases, the nurse also added "transition discussion" to the visit reason and scheduled these as extended-length visits. We completed this pilot when the three PCPs ran out of eligible patients for our team to approach.

2.4.3. Assessment

We tracked the number of eligible patients, the number of eligible patients who completed the scheduled appointment, the number of patients whose EHR contained "transition discussion" in the visit reason, the number of times transition goals were established and documented, whether transition goals required nurse follow up to support goal progress, and the number whose chart contained smart phrase documentation. After completion of this pilot, we conducted a 30-minute semi-structured interview (available upon request) with participating PCPs and the lead clinical nurse. We asked the same set of close-ended questions asked of the nurses in the first pilot, and about provider experience implementing the pilot. Lastly, we also drew on the notes from our IT and Advisory Team meetings to describe our experience implementing this pilot.

3. Results

3.1. Pilot #1: nurse-led transfer preparation

We identified 70 eligible patients, were given pediatric PCP approval to approach 17 (24%), and enrolled ten patients. Providers gave the following reasons for not permitting us to approach the remaining 53 (76%): the patient was not ready, the patient was experiencing active health problems, or the provider wanted to keep the patient on their panel for at least an additional year. Of the ten enrolled patients, only two completed the first nurse check-in about understanding the medical home. No patients progressed beyond this stage of the intervention. At the end of the study period, three of the ten enrolled patients had completed transfer, one had an upcoming appointment scheduled with an adult PCP, two were still actively receiving care from the pediatric clinic, three were lost to follow-up, and one patient was deceased (Fig. 2a).

Results from our anonymous survey of the five nurses who participated in the project showed that nurses thought the pilot project strengthened their connection with patients ($n = 3$) and strengthened ($n = 2$) or did not change ($n = 1$) their connections with families of patients (Table 1). Two nurses reported that their workload increased, and one reported no change. Two nurses reported that their stress level increased, and three reported no change, from this project. Three nurses also reported experiencing at least some frustration transitioning AYAMC. Two nurses reported not having yet had the opportunity to implement the intervention with a patient at the time of the survey, which we interpreted as the "don't know" responses (Table 1).

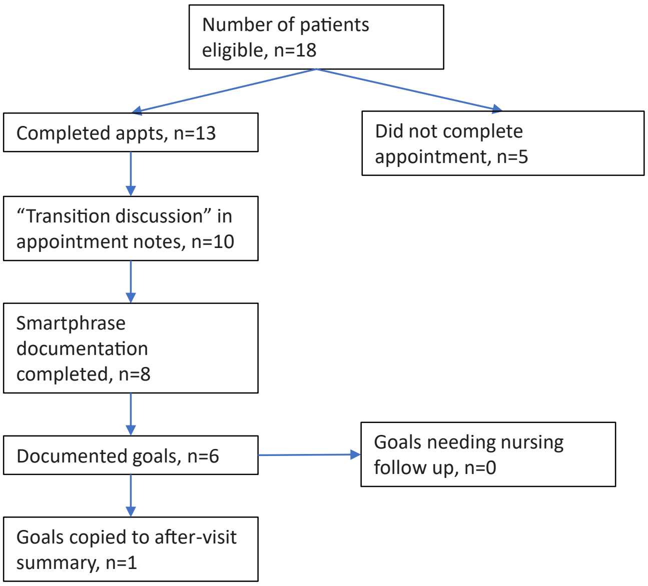


Fig. 2. Consort diagram showing participant study activity completion, for pilot Pilot #1 (a) and Pilot #2 (b).

Table 1
Pilot #1 nurse survey results.

Question & Response frequency n = 5
So far, how has this project influenced your connection with patients?
• Strengthened connection = 3
• Not changed connection = 0
• Weakened connection = 0
• Don't know = 2
So far, how has this project influenced your connection with families of patients?
• Strengthened connection = 2
• Not changed connection = 1
• Weakened connection = 0
• Don't know = 2
How has this project affected your typical weekly workload?
• Increased typical workload, change is manageable = 1
• Increased typical workload, change is barely manageable = 1
• Increased typical workload, change is not manageable = 0
• No change to typical workload = 1
• Decreased typical workload = 0
• Don't know = 2
How has this project affected your professional stress level?
• Increased stress level = 2
• Not affected stress level = 3
• Decreased stress level = 0
• Don't know = 0
How frustrating is it for you to transition young adults with medical complexity in this setting?
• A lot = 0
• Quite a bit = 1
• Some = 2
• A little bit = 0
• Not at all = 0
• Don't know = 2

Nurses who did have the opportunity to implement the intervention described to our lead clinic nurse that families often did not respond to voicemail messages or reply to messages sent through the EHR patient portal, in spite of multiple attempts. Nurses reported that families did not want to spend time discussing the medical home model or their youth's care team, medications, and medical conditions. Nurses reported that patients and families primarily focused on receiving support in identifying adult providers who would be a good fit for their youth's unique medical needs; patients and families indicated to nurses that they already knew much of this information or did not think it was relevant in their search for an adult provider. Additionally, our lead clinic nurse observed that it was necessary to have a designated EHR field for clinic staff to document a patient's enrollment status to facilitate communication and follow up with patients across clinic staff.

3.1.1. *Team reflection and context during COVID-19*

Results from the tracking data showed that our pilot did not unfold as we intended. Results suggested to our team that pediatric PCPs needed more than 12 months to prepare for their patients to transfer to adult PCPs. When we shared these results with our CoIIN Advisory Team, pediatric provider members who worked in the clinic stated that they would not talk about transition care in the following circumstances: when a family was experiencing a crisis, without having an adult provider identified, or when the time available during an acute care visit was needed to address other health concerns. Our clinical team members perceived that transition was a topic better broached first by the PCP and followed up on by a nurse or other staff member. Lastly, COVID-19 overburdened the institution's adult primary care clinics, which were not accepting new patients. These reflections and context informed the development of Pilot #2.

3.2. *Pilot #2: provider engagement in transition preparation*

In total, 13 of 18 identified patients scheduled and completed their appointments. Ten of the 13 patients had "transition discussion" written in their appointment notes, consistent with the intended workflow. Of the ten, the smart-phrase was documented in eight of the appointments. Six of the eight appointments documented the establishment of transition goals, and the provider copied the goals into the after-visit summary for one of the patients. None of the transition conversations required any nurse follow up to support identified goals. The remaining three of the 13 patients did not have "transition discussion" written in their appointment notes. There is no documentation of providers having discussed transition during the appointments with those patients (Fig. 2b).

Results from the three provider interviews showed that the pilot did not affect the provider's relationship with the patient and family or providers' stress level (Table 2). The pilot intervention increased their workload, but in a manageable way. Providers also reported experiencing some frustration with HCT at this institution, which was associated with not having an available, or trusted known, adult provider to whom they could refer patients. The lack of adult provider raised concerns for their patients' welfare, and in one case, also made the provider feel the transition discussion would be fruitless. Two additional points emerged from the interviews. First, they found it difficult to incorporate transition discussion and preparation in the midst of competing patient health priorities, even when extra time was given for the appointment. Providers shared that discussing distant, future transfer to another provider did not seem pertinent in the face of other acute concerns. Second, discussions demonstrated that providers could benefit from more detailed training about the process of health care transition. For example, some providers referenced the *transfer* stage, rather than the three-stage transition process (i.e., preparation, transfer, integration) when discussing transition,[5] and one pediatric PCP explicitly stated they needed specific training in how to talk with patients about transition. We implemented the 45-minute training after conducting these interviews.

4. Discussion

Primary care providers have an important role in supporting the transition of AYAMC to adult health care,[14] yet little has been written about such approaches.[16–18] The aim of our article was to describe our learning from implementing two sequential primary care transition pilots, during the COVID-19 pandemic, as part of a cross-state, multidisciplinary learning network. Our first pilot focused on transfer

Table 2
Pilot #2 pediatrician interview results.

Question and Response Option Frequency Counts
So far, how has this project influenced your relationship with patients?
• Strengthened connection = 0
• Not changed connection = 3
• Weakened connection = 0
• Don't know = 0
So far, how has this project influenced your relationship with families of patients?
• Strengthened connection = 0
• Not changed connection = 3
• Weakened connection = 0
• Don't know = 0
How has use of the transition dot phrase affected your typical workload for a young adult with medical complexity?
• Increased typical workload, change is manageable = 3
• Increased typical workload, change is barely manageable = 0
• Increased typical workload, change is not manageable = 0
• No change to typical workload = 0
• Decreased typical workload = 0
• Don't know = 0
How has this project affected your stress level at work?
• Increased stress level = 0
• Not affected stress level = 3
• Decreased stress level = 0
• Don't know = 0
How frustrating is it for you to prepare young adults with medical complexity for transition to adult health care in this setting?
• I experience a lot of frustration = 1
• I experience some frustration = 2
• I experience a little frustration = 0
• I do not experience frustration = 0
• Don't know = 0

preparation for older AYAMC. While the COVID-19 response halted our pilot, our team reflected on the challenges encountered and devised a second pilot that focused on supporting providers to engage in transfer preparation with younger AYAMC. Although we did not fully achieve our objectives, unique learning about pediatric to adult primary care transition for AYAMC emerged from our attempts.

By design, our first pilot condensed preparation for transfer to adult primary care into a one-year period for AYAMC ages 21 and older still receiving care in a pediatric clinic. Although we expected patient or caregiver reluctance about transferring care,[21–23] we did not expect provider reticence. The reasons that pediatric PCPs gave for not wanting our team to approach their patients centered on concern for their patient's well-being and patient attachment.[24] Pediatric PCPs also held off transition preparation with AYAMC because of a lack of adult PCP availability, consistent with findings from others' transition studies.[21,26,27] With few exceptions (e.g., terminally ill patients), AYAMC eventually will need to work with an adult PCP. Beginning conversations about HCT early and often aligns with standards of transition care,[5] and the requests of families of AYAMC (and CYSHCN more generally).[6,7,12,25]

Findings from our PCP interviews during our second pilot highlight the importance of providing transition preparation training to pediatric PCPs. Some providers equated *transition preparation* (i.e., the first of three stages in the transition process in which patient and caregiver health condition knowledge and skills are developed) to *transfer care* (i.e., "the circumscribed activities associated with leaving/terminating pediatric care to access care from providers who care for adults).[28] This confusion is emblematic of definitional challenges in the health care transition field,[28] and would explain, at least in part, PCP reluctance to discuss transition preparation with younger AYAMC that emerged in our first pilot. Our response was a 45-minute training designed to clarify the transition process and give concrete examples of age-appropriate transition topics with younger AYAMC. We do not know the extent to which this influenced provider behavior during care encounters; however, we successfully scheduled a virtual 45-minute meeting attended by all three (busy) pediatric PCPs during the COVID pandemic response. Future research is needed to better understand the effectiveness of such training for current providers. Additionally, future intervention efforts should ensure that adequate time (i.e., multiple years) is available to prepare AYAMC and their families, *and* ensure that pediatric providers are knowledgeable about transition preparation topics and how to address them in routine patient care.

In addition, until transition preparation becomes routinized, primary care transfer preparation for some AYAMC will occur in a condensed timeframe (e.g., one year or less). Our learning suggests that in those situations, having the PCP initiate the conversation could elevate its importance to the patient or family, and result in greater engagement. Our findings also suggest that patients and families welcome having the support of a nurse or care coordinator in locating an adult provider who accepts new patients and the patient's insurance, which also may increase engagement.

Findings also emphasize the importance of developing relationships with, and institutionalizing communication between, pediatric and adult PCPs.[21] Our clinical setting lacked established relationships with adult PCPs, which we were unable to attempt developing during the COVID-19 response. Our clinic also lacked a policy that specified an age, or age range, for completing transfer to adult primary care, the first of Got Transition's Six Core Elements.[5] In absence of provider relationships and policy, the timing of transition preparation and transfer determination is left to individual pediatricians' discretion. This approach is inconsistent with patient- and family-centered care, results in diminished capacity for pediatric clinics to add new *pediatric* patients to their panels, and contributes to AYAMC and their caregivers never receiving transition preparation. Future efforts to develop primary care HCT interventions for AYAMC should include establishing pediatric-adult provider relationships. In addition to easing pediatric PCP concerns, these relationships also may address adult PCP concerns about caring for AYAMC.[5,7,16]

Clinical infrastructure is needed to support pediatric PCPs to provide HCT. Our second pilot developed infrastructure to assist providers in initiating transition discussions with their AYAMC patients, and documenting the discussions in patients' EHR. Our numbers are small, but suggest that having "transition discussion" noted in the patient appointment and a smart phrase contributed to providers introducing transition with their patients (as reflected by EHR documentation).

To summarize, our results demonstrate that clinician education, relationships with adult clinics, and structured workflows embedding transition services within standards of adolescent care are necessary to consistently deliver transition interventions. An improvement science framework can help implement these practical implications for care delivery in a manner that allows for standardization within an individualized context.

4.1. *Limitations*

Our description reflects a single-center's experience of implementing two short duration pilots, and was limited by low enrollment and competing clinical demands. Project implementation occurred at the height of the COVID-19 response, and justifiably presented our medically complex patient population, their families, providers and clinical staff with more immediate priorities. Conversations about HCT require extra care and planning for clinicians unfamiliar with the content, which was difficult given the simultaneous, significant clinical practice changes underway in response to COVID. Our understanding of our second pilot project also is limited in that we lack data describing the quality of the HCT discussions between patient, family, and provider during care appointments. Collecting patient and family perspectives will be useful to future research.

5. Conclusions

Primary care has an important role to play in supporting AYAMC and their families prepare for transition and to transfer to adult health care. Our findings suggest that pediatric primary care providers require time, connection to adult PCPs, and educational support to realize this role.

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Ethical statement

The Institutional Review Board reviewed and provided oversight for this work. OHSU IRB# STUDY00019036, MOD00021418, STUDY00022163.

CRediT authorship contribution statement

Reem Hasan: Conceptualization, Methodology, Formal analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Supervision. **Reyna Lindert:** Methodology, Investigation, Resources, Writing – original draft, Writing – review & editing. **Danielle Sullivan:** Investigation, Resources, Writing – original draft, Writing – review & editing. **Shreya Roy:** Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Writing – review & editing, Project administration. **Alison J. Martin:** Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Writing – review & editing, Supervision, Project administration, Funding acquisition.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Alison Martin reports financial support was provided by Health Services and Resources Administration Maternal and Child Health Bureau.

Data availability

Data will be made available on request.

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