

# Development of a transition program for pediatric patients with renal disease

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## ABSTRACT

**Background:** The transition from pediatric to adult health care is challenging for patients with renal disease and inadequate transition can lead to increased disease-related morbidity. We developed a structured health care transition (HCT) program that includes a joint two-step transition clinic; the first step is the pediatric clinic and second step is the adult clinic.

**Methods:** Quality improvement methodology was utilized to establish an interdisciplinary transition team and conduct a needs assessment. Lack of a standardized HCT program was identified as a primary barrier to HCT. We utilized transition team and other stakeholder input to implement a transition program that included a joint pediatric/adult two-step transition clinic. Various other components were developed, including a transition policy and patient and provider feedback surveys. A pilot group of patients with kidney disease participated in the program.

**Results:** 27 patients completed the "first step" and 22 patients completed the "second step" of the transition clinic. Median age at the time of transition was 20 years, with kidney transplant (41 %) as the major diagnosis. All patients (100 %) received the transition policy and reported that the transition team worked with them to gain skills to manage their health and plan for the future. Pediatric and adult nephrologists reported feeling satisfied (100 %) with the transition program.

**Conclusion:** A structured transition program was established utilizing expertise of a dedicated transition team and was well received by participants. This program is a critical first step in addressing the gap in standardized care for transition for pediatric patients with kidney disease.

## 1. Introduction

Adolescents with pediatric-onset kidney disease are living longer<sup>1</sup> and are therefore more likely to experience healthcare transition (HCT), defined as the process of intentional and planned movement of adolescents and young adults with special healthcare needs (AYASHCN) from a pediatric-centered health care system to an adult-centered health-care system.<sup>2</sup> The 2018 AAP Clinical Report<sup>3</sup> provides several updated best practice advice recommendations for the healthcare transition process, including incorporation of HCT topics into routine visits and a focus on adult care integration. Experts have advocated for a "warm handoff"

between providers of AYASHCN, which is the transfer of care between pediatric and adult providers that occurs in the presence of patient and family.<sup>4</sup>

### 1.1. Problem description

Unfortunately, HCT can be a difficult and fragmented process partially due to logistic barriers such as locating an adult provider<sup>5</sup> and maintaining insurance coverage.<sup>6</sup> In addition to those factors, adolescence is a particularly challenging time to transition<sup>7</sup> with as many as 50 % of AYASHCN struggling to adhere to medications and attend

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appointments with the added challenges of starting college or seeking employment.<sup>8</sup> These challenges occur within the broader setting of developmentally typical aspects of adolescence such as risk-taking, increasing independence, and an increased reliance and focus on peers instead of parents. Inadequate HCT can lead to poor patient outcomes such as avoidable hospitalizations and even graft loss in patients with kidney transplants.<sup>9,10</sup> Therefore, there is a need for better HCT programs to help prepare patients for transition and to prevent negative patient health-related outcomes.

### 1.2. Rationale

Well-organized HCT, including the use of transition clinics, has been shown to improve patient outcomes, such as preventing graft loss in kidney transplant recipients, and is associated with decreased hospitalizations in AYASHCN with other chronic conditions.<sup>11</sup> Prior attempts to develop a clinic dedicated to health care transition have been met with varying success.<sup>12,13</sup> Reported difficulties and barriers in the transition to adult care include monitoring and preventing patient loss to follow up upon transition possibly due to the change in setting, insurance issues, poor preparation, inadequate handoff, as well as limitations in funding and staffing.<sup>4</sup> It has also been challenging to find an adult doctor appropriate to care for patients with chronic and complex diseases, as well as available and comfortable to accept the transitioning patient. Finally, there are many difficulties in garnering feedback from patients once they transition.<sup>13</sup> These experiences highlight the challenges of creating and implementing a well-organized transition program that serves patient needs and is sustainable within the hospital and outpatient settings.<sup>14</sup>

In this paper, we describe barriers to successful HCT at our institution and our team-based approach to create a structured HCT program utilizing elements recommended by Got Transition®. We highlight our collaborative quality improvement approach, beginning with creation of a transition team and policy, moving towards design and implementation of a novel joint two-step transition clinic to improve patient satisfaction and outcomes, and finally, assessment of the entire HCT program. Our specific aim was by December 2022, a structured renal HCT program will have been implemented and 30 eligible patients with kidney disease will have participated. Further, attending two adult appointments after transfer is one of the optimal outcome measures of successful transition,<sup>15,16</sup> and this is one of our goals as an outcome metric.

## 2. Methods

### 2.1. Context and stakeholders

This paper highlights a quality improvement approach to the creation of a transition program by incorporating many of the transition core elements from GOT Transition® recommended by the AAP (see Table 1) in the pediatric renal department of a large free standing children's hospital in collaboration with adult-nephrologists at an affiliate hospital in an urban part of the Southwestern USA. Both institutions utilize "Epic" as the mode for electronic medical records (EMR). Important stakeholders included patients and their caregivers, an adult nephrologist, pediatric nephrologists, and the pediatric transition team (lead by a pediatric nephrologist). The nephrologists involved in the transition program on both the pediatric and adult side who chose to participate were highly motivated to work with patients in preparation for transition to adult care.

### 2.2. Interventions

#### 2.2.1. Transition team

The pediatric transition team was created in 2019 and includes a nephrologist champion, renal psychologist, physician assistant, and

**Table 1**

Incorporation of transition core elements as recommended by AAP in our structured transition program.

Transition Core Elements	Procedure
Policy/ Guide	Transition policy and family letter was created by transition team and was discussed with patients by the transition navigator or social worker.
Tracking/ monitoring	Transition Navigator and social worker tracked patients eligible for transition in excel sheet.
Readiness	Transition Navigator and social worker assessed patients for readiness during clinic visits.
Planning	In collaboration with the primary pediatric nephrologist, the transition navigator and social worker helped patients plan for transition with respect to insurance, location, diagnosis and preferred nephrologist.
Transfer of care	Transfer of care to adult nephrologist included utilizing 2-step transition clinic for warm hand off and transfer of EMR.
Transition completion	The transition navigator confirmed adult appointment attendance and contacted patients around 6 months post transfer to elicit feedback.

allied health care professionals, such as a transition navigator, quality of life specialist, and social workers. The transition team met every two to four weeks to gather baseline information regarding current transition practices within the department, identify local barriers to appropriate transition of care, and problem-solve solutions to address barriers. These ongoing meetings sought to address the needs of patients, families, and health care providers. This transition team was heavily involved in the development of the structured transition program, which included a two-step clinic. The transition team consisted of several interdisciplinary members. The transition navigator's role included identifying patients qualifying for transition, working with the family and both pediatric and adult nephrologists to prepare and schedule transition clinic appointments, and serving as a consistent point of contact for the patient throughout the transition process and for at least two adult care visits. The social workers engaged with the patient by reviewing insurance needs, social concerns and providing resources throughout the entire process. The renal transplant physician assistant helped ensure the presence of a pediatric provider during clinic for kidney transplant patients in cases where the pediatric nephrologist was unavailable. The renal psychologist and quality of life specialist worked alongside the team during development and in an ongoing capacity to ensure a well-rounded approach to developing and maintaining the transition program. In particular, the psychologist provided psychoeducation to the team regarding transition-related research and the psychological considerations of transition for adolescents, as well as creating some of the surveys. The quality of life specialist offered ongoing general support, hands on education for choosing dialysis units or adult providers, and assisted in coordination of care for the transfer to adult care. The nephrologist champion supervised the development of the transition program and served as the physician liaison with other pediatric nephrologists in the department as well as the adult nephrologist at the affiliate hospital.

#### 2.2.2. Transition needs assessment

A needs assessment survey to assess current transition practices from the pediatric nephrologists' perspective was done between December 2019 and January 2020. Based on the results of the survey (Table 2), as well as needs identified in meetings with the transition team, an Ishikawa fishbone diagram was utilized to identify system gaps and barriers to successful transition. Our department survey confirmed the following barriers to successful HCT: (1) lack of standardized transition planning, (2) lack of a dedicated transition clinic, (3) underutilization of a transition readiness tool, (4) difficulty finding an adult nephrologist, and (5) inadequate health care insurance. These identified barriers were similar to ones acknowledged in HCT literature.<sup>5,6</sup> The pediatric nephrologists' average rating for ease of transition prior to initiation of HCT program

**Table 2**

Results of physician needs assessment survey (n = 17).

		N (%)
Rate the ease of transition (5 =high ease), Mean $\pm$ SD		2.5 $\pm$ 0.92
Age in years to start discussions about transition	12	1 (6)
	14–15	7 (41)
	17–18	7 (41)
	No set age	2 (12)
A process for transition is routinely used	Yes	2 (12)
	No	3 (18)
	Sometimes	9 (53)
	No answer	3 (18)
Utilization of transition readiness tool	Yes	4 (24)
	No	7 (41)
	Sometimes	6 (35)
Age in years for transition to adult care	18–21	16 (94)
	22–25	1 (6)
Do you want to take care of patients above age 21 years?	Yes	3 (18)
	No	14 (82)
Highest obstacles to transition	Insurance	7 (41)
	Lack of patient satisfaction	2 (12)
	Complex care needs	4 (23)
	Finding an adult nephrologist	2 (12)
	Lack of care team time	2 (12)

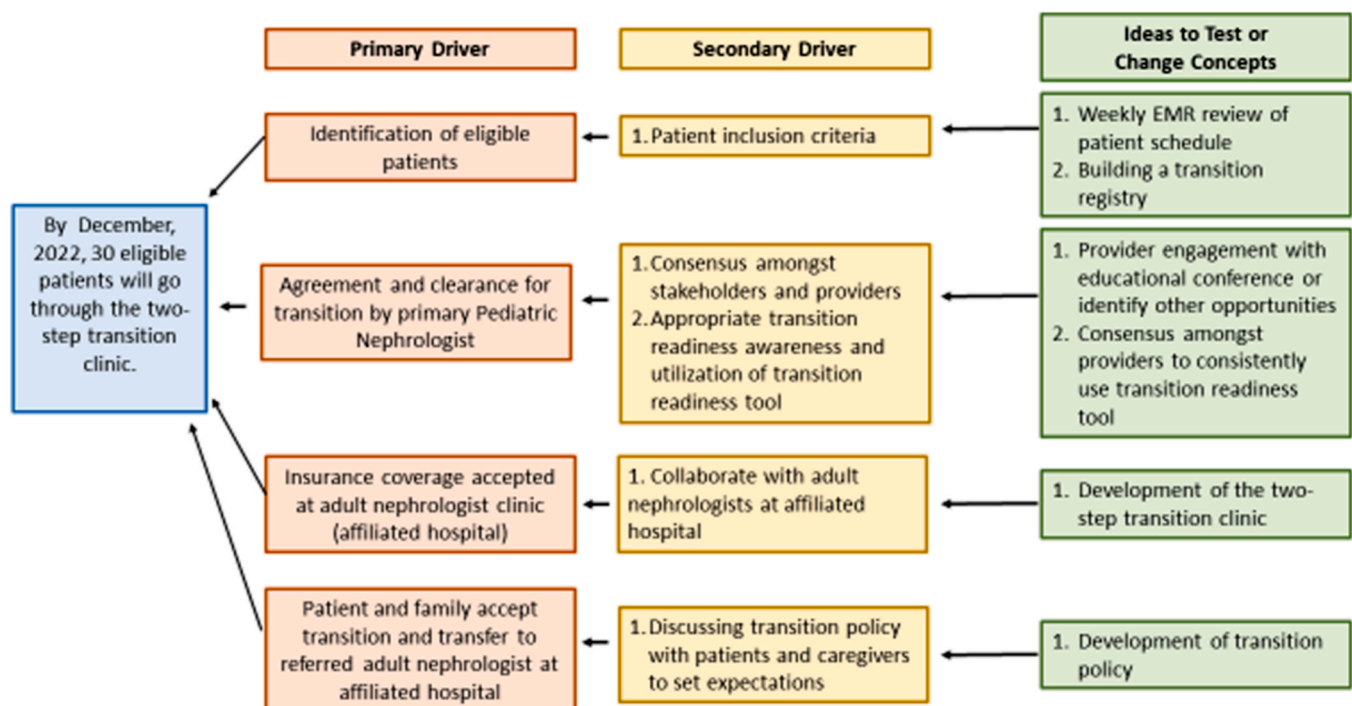
was 2.5 out of 5 with 5 being “smooth/easy” transition. These results further supported the need to improve the quality of transition to adult care for the renal patients served by our institution.

**Lack of standardized transition planning.** The needs assessment revealed that HCT practice varied widely within our department and was highly dependent on each pediatric nephrologists’ discretion, including the inconsistent use of an EMR based transition readiness tool, the age to begin transition preparation, and the eventual transfer to adult care. Moreover, there was no formal sign-off process between the pediatric and adult renal teams; patient records were transmitted via fax or EMR by the nurse or social worker, with no verbal communication between the pediatric and adult teams.

### 2.3. Change strategies

To begin to address the need for a standardized HCT program, key drivers were identified (Fig. 1). The first step was to develop a department transition policy that the transition navigator discussed with all patients. The team also created a family letter to set expectations and help cultivate a positive attitude regarding transitioning to adult care. A collaboration was formed with the adult nephrologist at the affiliate hospital. All pediatric nephrologists at the institution received initial education at the monthly departmental meeting regarding the significance of a structured transition program and its implementation; their questions and concerns were further addressed at monthly faculty meetings and through annual educational conferences addressing health care transition guidelines and developments in the program. Subsequent steps included selecting a pilot group of patients with kidney disease to go through the transition program, and collecting patient feedback regarding the quality of their transition experience. Patients completed the pre-transfer survey at the “first step” of the transition clinic and the post-transfer survey was completed at around 6 months after the “second step” of the transition clinic. These surveys provided valuable feedback at multiple points in the transition process and were taken into consideration to improve the transition program. See Fig. 2 for timeline of events in the development of the transition program.

**Two-step Transition Clinic.** The team reviewed the needs assessment and determined that a missing element was a “warm handoff” between the pediatric and adult nephrologist; the two-step clinic was developed to address that identified gap in care. “Warm handoffs” are typically well-received by patients and help with continuity of care.<sup>4,17</sup> The workflow of the “first step” of the transition clinic involved a clinic visit with both the pediatric nephrologist and adult nephrologist at the pediatric renal clinic with the patient and caregiver, when available (Fig. 3). During this clinic, members of the transition team, notably the pediatric social worker and the pediatric transition navigator, also met with the patient and family to address any additional issues related to transition, such as insurance coverage. The “second step” of the transition clinic then occurred with the adult nephrologist at an affiliate hospital joined by the pediatric nephrologist and transition navigator.

**Fig. 1.** Key Driver Diagram.

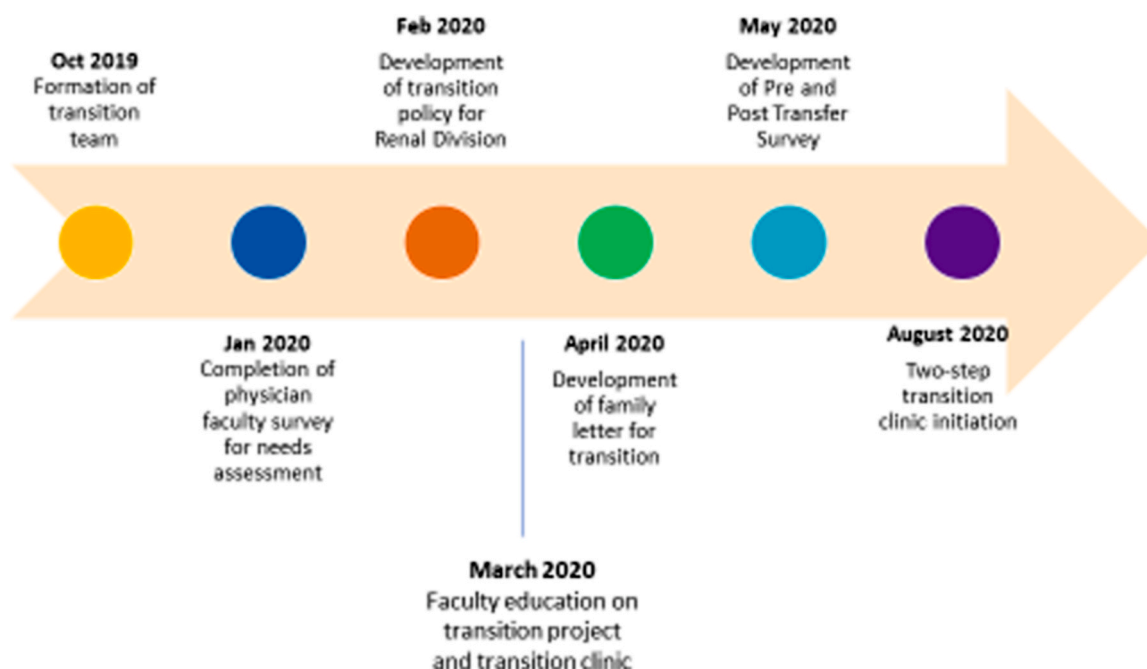


Fig. 2. Timeline of Transition Process Development.

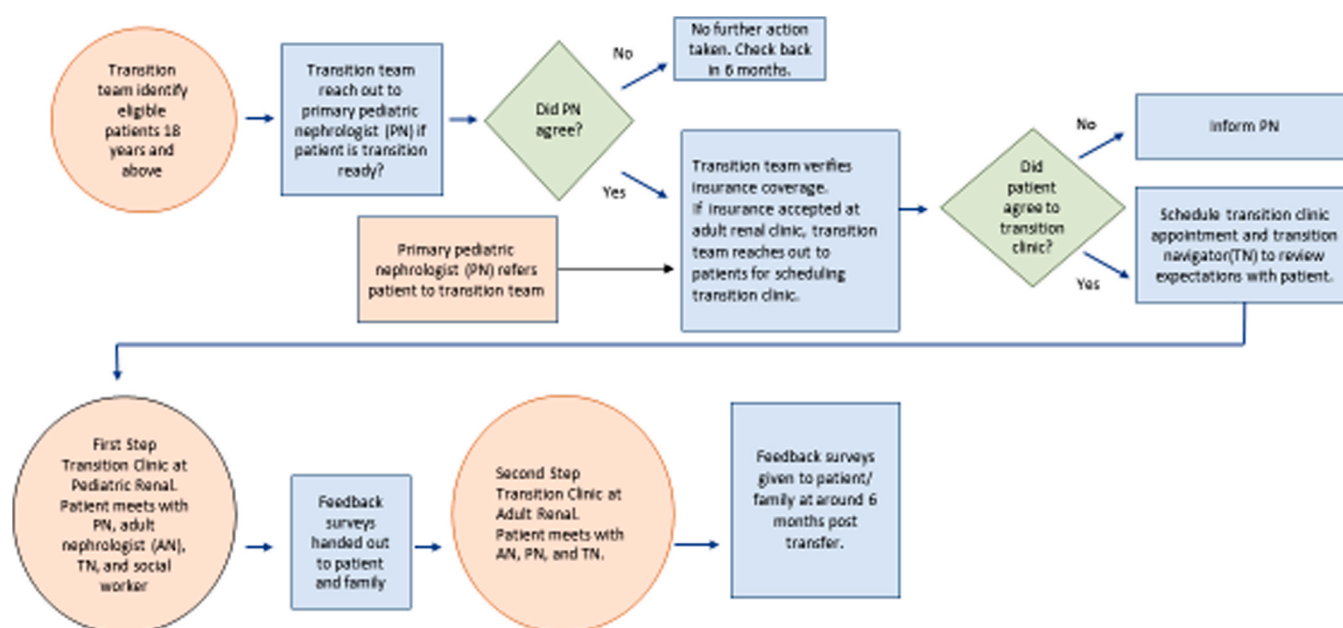


Fig. 3. Process map for the two-step transition clinic.

The two-step transition clinic provided a platform for patients and nephrologists to be part of a personalized transition experience and discuss the patient's medical condition and plan of care.

#### 2.4. Target population

A pilot group of 16 patients with lupus nephritis or polycystic kidney disease was identified by their primary pediatric nephrologist as transition-ready within the new transition program. The initial pilot group included patients with stable medical conditions except for one patient who was pending dialysis and needed to establish care in an adult dialysis unit. The transition program was well received, as indicated by patient survey and provider verbal feedback. Therefore, the

recruitment population was further expanded after six months to include 11 patients with more complex conditions like renal transplant and other chronic kidney diseases who require a more robust transition support.

#### 2.5. Metrics

Outcome metrics in this project included attendance at the two-step renal transition clinic as well as an additional visit to the adult clinic in the time frame recommended by the pediatric and adult nephrologists. Process metrics included identifying patients eligible for the transition program, tracking the number of patients who received the transition policy and who experienced transition planning with the social worker



and transition navigator, and successful transfer of the EMR. We utilized nephrologist satisfaction surveys as well as patient feedback in the form of pre-transfer and post-transfer clinic surveys, which also assisted in improving the structure of the transition program. Patient feedback regarding the current transition program, including the two-step clinic, focused on: (1) preparation for transition, (2) the transition process, and (3) perceived areas of strength as well as areas for improvement. We defined successful transfer to adult health care as a patient completing at least two visits with the adult nephrologist including the “second step” clinic visit. Balancing measures included reduced compensation and increased time effort by providers.

## 2.6. Analysis

Descriptive statistics were used to analyze the quantitative data. Answers to open-ended questions were collated, reviewed, and summarized by the investigative team.

## 3. Results

### 3.1. Demographic characteristics of patients in the transition program

Between August 2020 and December 2022, the transition program, including the two-step transition clinic was utilized for 27 patients, with more female (63 %) than male (37 %) participants. Most patients were of Hispanic (59 %) background and most patients' primary diagnosis was kidney transplant (41 %) (Table 3).

### 3.2. Outcome measures

The outcome measure used was patient attendance at the two-step renal transition clinic; the “first step” was completed by 27 patients, and 22 patients completed the “second step”. Of the 22 patients who have completed both steps, 16 (73 %) patients have had two or more appointments with the adult nephrologist within the recommended time frame as determined by disease complexity and discussions among pediatric and adult nephrologists. Of note, of the five patients who have yet to complete the “second step,” two patients had to work with the transition team to acquire a community-based health plan after an unforeseen change of insurance in order to continue to receive care with the adult nephrologist. Two patients were lost to follow up despite multiple phone calls and one of these patients has a pending appointment.

### 3.3. Process measures

All participants (100 %) reported they received the transition policy, were engaged in transition planning, and had successful transfer of medical records.

In the pre-transfer survey (see Table 4), given at the “first step” clinic

**Table 3**  
Demographic characteristics of patients in Two-step Transition Clinic (n = 27).

Demographic characteristic	N (%)
Gender	
Female	17 (63)
Male	10 (37)
Race/ethnicity	
African-American	4 (15)
Non-Hispanic White	4 (15)
Hispanic	16 (59)
Other	3 (11)
Diagnosis	
Lupus Nephritis	10 (37)
Polycystic Kidney Disease	1 (4)
Chronic Kidney Disease	5 (18)
Renal Transplant	11 (41)
Age in years	
18–20	19 (73)
≥21	8 (27)
Insurance status	
Public	19 (70)
Private	8 (30)

**Table 4**

Pre-transfer survey completed by nephrology patients (n = 25).

Construct	Response	N (%)
<b>Transition Policy</b>		
Renal team has a policy and discusses it with me*	Yes	24/24 (100)
<b>Transition Readiness/Self-Management skills</b>		
How often I schedule my own appointments*	Always	10/24 (42)
	Usually	2/24 (8)
	Sometimes	5/24 (21)
	Never	7/24 (29)
I talk with my Renal doctor without my parent/caregiver*	Yes	14/24 (58)
	No	10/24 (42)
Renal team explains things in a way I understand	Always	24/25 (96)
	Usually	1/25 (4)
Renal team respects my customs/beliefs affect care*	A lot	23/23 (100)
Renal team works with me to gain skills for self-management*	A lot	16/20 (80)
	Some	4/20 (20)
<b>Transition Planning</b>		
Renal team explained legal changes at age 18*	Yes	22/22 (100)
Renal team shared and explained medical summary*	Yes	23/23 (100)
Renal team has information about community resources*	Yes	19/22 (86)
	No	2/22 (9)
	Don't Know	1/22 (5)
Renal team works with me to plan for the future*	A lot	17/24 (71)
	Some	7/24 (29)
<b>Transfer of Care</b>		
I know how I will be insured as adult*	Yes	16/24 (67)
	No	6/24 (25)
	Somewhat	1/24 (4)
	Don't know	1/24 (4)
I understand the role of an adult renal doctor*	Yes	22/23 (96)
	Don't know	1/23 (4)
Renal team assists in identifying new adult provider*	Yes	23/24 (96)
	No	1/24 (4)
I feel prepared to change to an adult renal provider	Very prepared	8/25 (32)
	prepared	15/25 (60)
	Somewhat	2/25 (8)
	Not prepared	

Note: \* denotes missing responses for that item

visit, when asked whether patients felt prepared for transition, 32 % (n = 8) responded that they were very prepared, 60 % (n = 15) were somewhat prepared, and 8 % (n = 2) felt not prepared. A little over half (58 %, n = 14) said they had talked with a doctor alone. Further, 100 % of the patients who responded reported that their renal team worked with them “a lot” or “some” to gain skills to manage their health and to plan for the future. All patients (100 %) reported feeling like the medical team was listening to them.

Post transfer satisfaction surveys were completed six months' post-transition to adult care by 15 of the 16 patients who had seen their adult nephrologist at least twice (see Table 5). Overall, 93 % (n = 14/15) patients reported they were satisfied with the transition process. Fifty percent (n = 7/14) reported being “satisfied” and 29 % (n = 4/14) reported they were “somewhat satisfied” with their new adult nephrologist. A total of 87 % (n = 13/15) reported they were “somewhat likely” or “very likely” to return to their adult nephrologist and 87 % (n = 13/15) reported they would recommend their adult nephrologist to others. One patient indicated they would like another option for possible adult nephrologists. When asked how the pediatric team could have made the overall transition better, nine patients responded with positive comments such as “nothing” or “it was great,” and one patient was unsure if any changes were needed. When asked what ideas patients had for their adult doctor in terms of welcoming new young adult patients into their service, three patient responses included increased or better communication, one patient wanted someone to speak with them about their plans for the future, and six had no additional comments.

**Nephrologist Satisfaction Survey.** Six pediatric nephrologists participated in the two-step transition clinic model and all six completed the satisfaction survey of the newly implemented structured HCT program,

**Table 5**  
Post-transfer survey completed by nephrology patients (n = 15).

Construct	Response	N (%)
<b>Preparation by Pediatric Team</b>		
How prepared did you feel to change to an adult health care provider?	Somewhat	14/15 (93)
	Very	1/15 (7)
Did you know how you would be insured as you became an adult?*	Yes	5/12 (42)
	No	6/12 (50)
	Somewhat	1/12 (8)
Did you understand the role of the adult renal doctor before you transitioned?	Yes	13/15 (87)
	No	2/15 (13)
How satisfied are you with the transition process?	Satisfied	14/15 (93)
	Not at all satisfied	1/15 (7)
<b>Transfer to Adult Care</b>		
Did your adult renal doctor have your medical records yet?	Yes	15 (100)
<b>Adult Care Team</b>		
Did your adult renal doctor (or their office staff) provide written or online information describing their hours and services?	Yes	3/15 (20)
	No	12/15 (80)
Did your adult renal doctor or their office staff explain how to reach the office online or by phone for medical information, test results, medical records, or appointment information?*	Yes	13/14 (93)
	No	1/14 (7)
How often does your adult renal team listen to your story?*	Always	2/14 (14)
	Usually	11/14 (79)
	Sometimes	1/14 (7)
How often does your adult renal team explain things in a way that is easy to understand?*	Always	2/14 (14)
	Usually	11/14 (79)
	Sometimes	1/14 (7)
Does your adult renal team actively work with you to think about and plan for the future?*	No	14/14 (100)
Does your adult renal team have information about community resources?	No	15/15 (100)
How satisfied are you with your new adult doctor/clinic?*	Satisfied	7/14 (50)
	Somewhat	4/14 (29)
	Neutral	2/14 (14)
	Not at all satisfied	1/14 (7)
How likely are you to return to the same adult doctor/clinic?	Very Likely	6/15 (40)
	Somewhat	7/15 (47)
	Neutral	1/15 (7)
	Not at all likely	1/15 (7)
Would you recommend your adult doctor to others?	Yes	13/15 (87)
	No	1/15 (7)
	I don't know	1/15 (7)

Note: \* denotes missing responses for that item. Numbers may not sum to 100 % due to rounding.

indicating they were either “very satisfied” (67 %) or “satisfied” (33 %) with the overall transition program. They also reported feeling “very satisfied” (83 %) or “satisfied” (17 %) with the two-step transition clinic model as a component of the HCT program. All (100 %) stated they would recommend this model for other patients and that they would recommend the adult nephrologist again for some other patients. These pediatric nephrologists also rated the transition team as “extremely helpful” (50 %) or “very helpful” (50 %).

The six pediatric nephrologists who were able to attend the two-step transition clinic were a mix of junior and senior faculty with varying clinical expertise and hence broadly represented the entire team of pediatric nephrologists (almost 20) in our department. Though the pediatric nephrologists were not directly involved in the designing phase of the HCT program, they completed a survey through which they contributed suggestions to improve the transition program. One suggestion was to incorporate the EMR to streamline logistical parts of the process, such as forwarding new referrals to the adult nephrologist and creating a transition registry. One nephrologist voiced how challenging it was to see patients at the adult nephrologist clinic due to scheduling and travel difficulties, although they noted the benefit of having both a pediatric and adult nephrologist at the appointment. Most nephrologists wanted “better incorporation of the transition readiness assessment” and

a list of possible adult nephrologists to provide to patients.

The adult nephrologist was “very satisfied” (100 %) with overall transition program and the 2-step transition clinic. The adult nephrologist also rated the transition as “extremely helpful” (100 %). Adult nephrologist commented on increasing the frequency of the transition clinic to monthly visits instead of every 2–3 months.

### 3.4. Balancing measures

There was an increased workload and lost relative value unit (RVU) or reimbursement for the second provider joining the two-step clinic. Specifically, the adult nephrologist was not able to bill for the “first step” at the pediatric renal clinic and the pediatric nephrologist was not able to bill for the “second step” at the adult renal clinic. There was also a significant time demand for both nephrologists to find a time that worked for both the adult nephrologist and pediatric team. Though robust, the hand off and interactions in clinic demanded about 1–2 h for each provider in the “first step” and “second step,” with only one step that was reimbursable per nephrologist.

## 4. Discussion

Using a quality improvement framework, we addressed the gap in standardized HCT care for AYASHCN with renal disease by establishing a structured transition program with a unique two-step transition clinic. This program has been well-received by patients and both pediatric and adult nephrologists. Although we did not reach our goal of 30 participants, there were 27 patients who participated in the initial half of the two-step clinic. Of those, 21 patients successfully completed the “second step” of transfer to adult health care. This was an incredible feat during a global pandemic that prompted a significant decline in in-person visits. Further, our overall transfer gap from pediatric to adult health care is acceptable and is aligned with average national standards for other chronic health conditions.<sup>18,19</sup>

### 4.1. Lessons learned and implications for practice

With respect to balancing measures, the additional time commitment required for both pediatric and adult providers to attend the two-step clinic was a challenge. Each nephrologist spent time not only seeing the patient at a visit without reimbursement but also traveling to and from the other clinic at some point in the program. Lack of reimbursement for visits is a challenge that has been documented in the literature and there is a national policy movement to support concurrent reimbursement in the healthcare transition realm.<sup>20</sup>

Discussion among the transition team and patients highlighted a need for a culture shift to view transition as a positive event for patients; it was something to be celebrated. The team incorporated a celebratory culture by providing patients with a graduation-like event at their “first-step” clinic visit which included a banner, goody bag, and graduation certificate. Anecdotal discussions among patients indicated patients enjoyed this celebration and thought it should be utilized for all transitioning patients.

Patients also told us they wanted more sexual education, including the review of teratogenic medications and contraceptives. We were able to utilize department funds to acquire a supply of condoms to distribute to our patients during transition clinic visits, as requested.

Formal feedback from patients’ post-transfer indicated a lack of information regarding community resources like insurance access from the adult nephrology team, the need for additional support to help patients navigate access to care issues that may arise after transition to adult care. It may be beneficial for the adult nephrologist to have an adult social worker on their team or at their hospital who is dedicated to AYASHCN or a transition coordinator counterpart in the adult setting to help patients. Alternatively, if these resources are unavailable, patients would benefit from continued support from their pediatric social worker

and transition navigator for a pre-determined amount of time (e.g., 6–12 months) after transfer to assist with access to care issues during the transition process.

Obtaining and maintaining health insurance continues to be one of the biggest barriers to transition for AYAHSN. For example, a patient who experienced a change in insurance three months post-transfer was unable to follow up with the adult nephrologist. After contacting the pediatric social worker, she was able to get assistance to re-establish insurance and continue in the adult clinic. Interestingly, patient views shifted such that in pediatric care, 72 % ( $n = 13$ ) reported they knew how they would be insured as an adult versus post-transfer, only 42 % ( $n = 5$ ) reported they knew how they would be insured as an adult; this highlights the confusing and uncertain nature of insurance in adult healthcare.

#### 4.2. Strengths of the program

This quality improvement approach highlighted several strengths in our team's unique approach to address the gap in transition care. First, the transition team utilized a holistic approach and worked together to help patients plan and prepare for the future. This included efforts by the social worker who helped patients secure insurance coverage to help ensure continuity of care. The second unique and key piece of our program was the configuration of the two-step clinic and creating a warm handoff between the pediatric and adult nephrologists. This effectively addressed the lack of a sign off process between providers. Although patient satisfaction data were not collected prior to implementation of this transition program to provide a baseline, the pre-transfer data were promising and showed a good foundation as we developed the program.

#### 4.3. Limitations

There were several limitations to this quality improvement project. The inability for both pediatric and adult nephrologists to bill for a joint visit will likely impact the sustainability of this program. The generalizability of our findings is limited by the small number of patients with kidney disease who were chosen to pilot the two-step transition clinic. Further improvement with a broader range and group of patients is needed. We were also unable to explore health status outcomes of the patients who completed the two-step clinic as compared to those who transitioned outside of the clinic.

### 5. Conclusions and future directions

There are several avenues to expand this QI project going forward. Additional opportunities for improvement of the transition process include a transition checklist to incorporate items such as a formal transition readiness tool.<sup>12</sup> Pediatric nephrologist feedback indicated a need for a dynamic transition registry that could be incorporated within the EMR and highlighted a need for a transition readiness tool. The team is working to incorporate a readiness tool like the TRxANSITION Index for patients with kidney disease; ideally, this would be utilized consistently by the transition navigator and social worker who would inform providers about patients' needs in preparation for transition (e.g., meeting alone with provider, scheduling appointments). In addition, there is ongoing discussion to have quarterly meetings with adult nephrologists in order to monitor success of patients post transition in regard to adherence to clinic visits and health-related outcomes for at least a year after transfer to adult care.

The pediatric nephrologists indicated that it would be helpful to have a list of adult nephrologists who are accepting new patients and interested in taking care of young adults so that patients could have more choices. Ideally, the two-step clinic would then expand to include additional adult nephrologists. Another possibility includes the option for a telehealth two-step clinic, which though not feasible in the current project, might be helpful in the future to increase accessibility and

provider options.

Pediatric patients with renal disease are living longer and undergoing the challenging and necessary process of healthcare transition. Inadequate healthcare transition can lead to poor health outcomes within this population; thus, it is crucial to improve the transition process. By using a quality improvement framework, this QI project utilized a structured transition program including the two-step clinic that was well-received by patients and physicians. Keys to success with this transition program thus far were (1) a *dedicated* transition team, (2) the two-step clinic where patients met with *both* their pediatric and adult nephrologists for collaborative care and (3) buy-in from both the pediatric and adult nephrologist, as well as the patient. Overall, this quality improvement approach resulted in a good foundation to build upon and continue to strengthen the transition process and address additional challenges.

#### Ethical statement

Hereby, I Constance Wiemann, consciously assure that for the manuscript "Development of a Transition Program for a Pediatric Renal Department in collaboration with an Adult Renal Department: A Quality Improvement Approach" the following is fulfilled:

- 1) This material is the authors' own original work, which has not been previously published elsewhere.
- 2) The paper is not currently being considered for publication elsewhere.
- 3) The paper reflects the authors' own research and analysis in a truthful and complete manner.
- 4) The paper properly credits the meaningful contributions of co-authors and co-researchers.
- 5) The results are appropriately placed in the context of prior and existing research.
- 6) All sources used are properly disclosed (correct citation). Literally copying of text must be indicated as such by using quotation marks and giving proper reference.
- 7) All authors have been personally and actively involved in substantial work leading to the paper, and will take public responsibility for its content.

The violation of the Ethical Statement rules may result in severe consequences.

To verify originality, your article may be checked by the originality detection software iThenticate. See also <http://www.elsevier.com/editors/plagdetect>.

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#### CRediT authorship contribution statement

**Sahar Siddiqui:** Conceptualization, methodology, Writing Original draft, Reviewing and Editing, Investigation. **Cortney Taylor Zimmerman:** Methodology, Writing- Reviewing and Editing, Data curation. **Brittany Garza:** Writing- Reviewing and Editing, Investigation, Resources. **Sai Kaumudi Saridey:** Methodology, Reviewing and Editing. **Constance M. Wiemann:** Methodology, Supervision, Writing – Reviewing and Editing.

#### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Data Availability

Data will be made available on request.

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