

Transitioning Young Adult Patients from Pediatric to Adult Rheumatology Practices in Rhode Island

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ABSTRACT

BACKGROUND: Young adults with rheumatic conditions encounter challenges when transitioning to an adult rheumatologist. At the Hasbro Pediatric Rheumatology Clinic, patients aged 18 and older were historically provided a list of adult rheumatologists; however, no formal transition process existed. We assessed the feasibility and acceptability of a pilot model to systematically transition pediatric patients to an adult rheumatologist using aspects of the Six Core Elements of Health Care Transition (HCT) from Got Transition®.

METHODS: A multidisciplinary team facilitated the program. Eligibility included: 18 years of age with stable, confirmed (or suspected) rheumatic disease. Program structure was implemented across three pediatric and one adult visit. Patient-reported transition readiness was assessed at initial and final pediatric visits using the Transition Readiness Assessment (TRA) from Got Transition®.

RESULTS: Sixty-four patients aged 18 and older had appointments with the Hasbro Pediatric Rheumatology Clinic from May 1, 2024 to Jan. 31, 2025. Thirteen were eligible; eight entered the pilot (61.5%). The mean age at recruitment was 19.5 years (range: 18–23). The study achieved a 62.5% retention rate, with 80% completion of video visits with adult rheumatologists and zero no-shows. TRA scores were high at baseline, although of note patients initially scored their readiness lower in areas related to transition confidence and navigating health care. The greatest mean score increase was seen for navigating health care (+2.7).

CONCLUSION: This rheumatology transition pilot demonstrated preliminary feasibility. Systemic changes to reimbursement and clinician education are needed to support HCT sustainability.

KEYWORDS: transition to adult care; rheumatology; adolescent; young adult; chronic medical condition

an increasing number of them require continued care into adulthood.¹ It is estimated that nearly 20% of children and young adults in the United States live with a complex chronic condition.² Transition from pediatric to adult care is a complex process known as health care transition (HCT), which should include three aims: planning, transfer, and integration of the patient into adult care. Less than 20% of pediatric patients across all subspecialties receive appropriate HCT, which should include discussion regarding transition spanning multiple appointments, beginning as early as ages 12–14.³ Appropriate HCT per meta-analysis data has been shown to improve adherence to care, the patient's quality of life, and self-care skills.⁴

The transition from pediatric to adult healthcare systems is particularly important in rheumatology, as most childhood rheumatic conditions are chronic and patients require regular, ongoing care. Several professional organizations, such as the American Academy of Pediatrics (AAP) and the American College of Physicians (ACP), have developed consensus statements for appropriate HCT.⁵ While some medical centers have designed HCT programs using these guidelines, standardization varies widely. Got Transition® is one organization that has been an innovator in the creation of a standardized approach for HCT, known as the Six Core Elements of HCT. This approach includes: transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer of care, and transfer completion.⁶ The American College of Rheumatology (ACR) has adopted Got Transition® practices and developed a transition toolkit.⁷

In Rhode Island, one pediatric rheumatologist at Hasbro Children's Hospital provides care for patients with childhood-onset rheumatic conditions. Rheumatology care for adult patients is split between academic and hospital-based group practices. Unlike academic medical centers where comprehensive pediatric and adult care is available within the same or adjacent facilities, pediatric and adult academic rheumatology practices in Rhode Island operate in different locations. Most adult rheumatology care in greater Providence spreads across three locations: Brown Medicine, an academic multispecialty practice in East Providence, Rhode Island; Brown University Health Rheumatology, a private multispecialty practice in Pawtucket, Rhode Island; and the Center for Primary Care in Providence, Rhode Island, staffed

INTRODUCTION

Children with complex chronic illnesses such as systemic lupus erythematosus (SLE), cystic fibrosis (CF), and inflammatory bowel disease (IBD) are living longer, and

by fellows from the Brown Rheumatology Fellowship Program. The fragmented nature of rheumatology care for adult patients in Rhode Island likely contributes to a challenging transition from one system to another.

Prior to this study, discussion regarding transition began at age 18 at the Hasbro Pediatric Rheumatology Clinic, which was significantly later than recommended. Furthermore, while these patients were told they should start to find an adult rheumatologist, no formal transition process existed. Recognizing the gaps in care that existed for transition-age rheumatology patients, we sought to develop and pilot a formal HCT pathway to prepare and facilitate the transition for these patients. Additionally, we aimed to reduce the geographic dispersion of pediatric and adult sites through a novel, video, warm hand-off between the pediatric and adult rheumatology teams during patients' final pediatric visits. The goal of this study was to assess the feasibility and acceptability of the pathway for transition-age patients and clinicians, and to investigate its preliminary role in shaping patient transition readiness.

METHODS

Study Setting and Team

This study employed a single-arm, prospective pilot and feasibility design. To facilitate the pilot, a team of pediatric and adult physicians and ancillary staff was established. This team included one research assistant, two primary care physicians with an interest in HCT, one pediatric rheumatologist, 10 adult rheumatologists (attendings and fellows), as well as practice managers. The pediatric rheumatology team determined appropriate patients for this pilot.

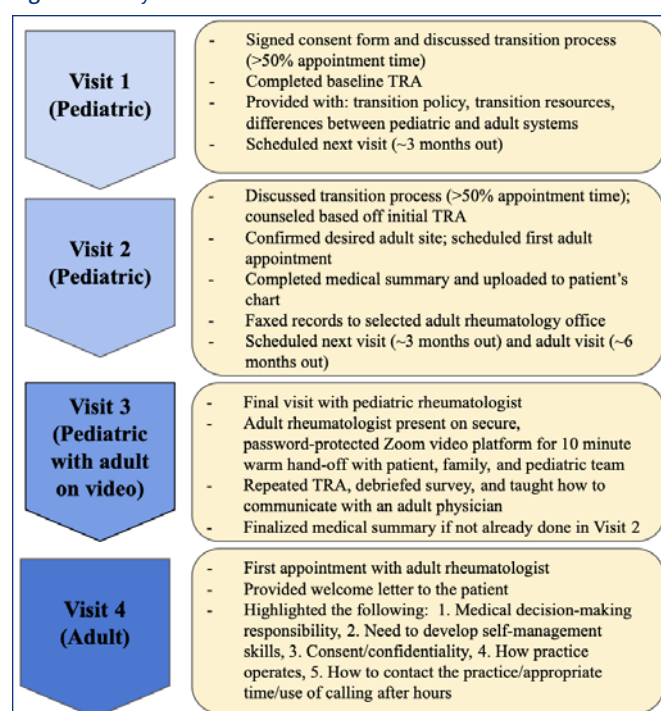
Patient Selection and Eligibility

The targeted sample size was 10–15 patients. Eligibility criteria included: age 18 and older, confirmed or suspected rheumatic disease, stable disease and/or in clinical remission, English-speaking, and seen by the pediatric rheumatology team within the last six months. These patients were approached by a member of the research team during their regular scheduled pediatric appointment. Patients who were seen by telehealth were not eligible for this study, to ensure consistent delivery of paper consent forms and transition materials, as well as in-person counseling. All study recruitment, transition-related education and counseling, and joint adult and pediatric provider video visits took place during patients' scheduled rheumatology appointments, and there was no separate billing for this work during either pediatric or adult visits. The research assistant led recruitment and counseling for the pilot; however, the program was designed such that a nurse or other allied health professional could replicate it in future iterations. This study was approved by the Brown University Health Institutional Review Board (IRB #2065997-5).

Study Protocol

For this study, patients engaged in a series of four visits: two with the pediatric rheumatologist; one with the pediatric rheumatologist and the adult rheumatologist, if possible, on video; and one visit with the adult rheumatologist. These visits were based upon various elements of Got Transition[®], with a particular focus on transfer of care and transfer completion. The complete protocol is detailed in **Figure 1**. Transition readiness was assessed at baseline and final pediatric appointments (Visits 1 and 3) using the Transition Readiness Assessment (TRA) from Got Transition[®] (**Appendix A [Email author for appendices]**). This was a validated survey that assessed patient transition readiness across four domains: self-perceived importance of transition to adult care; confidence in ability to transition from pediatric to adult care; managing individual health needs; and using health care.

Figure 1. Study Protocol



Data Analysis

The primary aim of this study was feasibility, as measured by recruitment rate (percentage of eligible patients enrolled), retention rate (percentage of patients completing all four appointments), and the percentage of patients receiving a joint video hand-off. Successful feasibility metrics were defined as: >50% recruitment rate, >50% retention, and >50% completion of video hand-offs. Patient demographics, including select social determinants of health (transportation access, insurance type), were abstracted from Epic and from patient interviews. The secondary aim included preliminary patient transition readiness, which was assessed by patient transition readiness assessment (TRA) scores

completed during the initial and final pediatric visits. Data were analyzed using descriptive statistics and individual-level changes due to the small sample size. Categorical variables (feasibility outcomes and demographics) are reported with frequencies. Continuous variables (TRA scores) are displayed with means and standard deviations to show the impact on the overall cohort and individual variability.

RESULTS

Sixty-four patients aged 18 and older had appointments scheduled during the recruitment period, from May 1, 2024 to Jan. 31, 2025 [Figure 2]. Of these, 13 patients (20.3%) were eligible and approached. The other 51 patients were excluded due to: virtual appointment, no suspected or confirmed rheumatic disease, no-show, or clinical instability. Ultimately, eight patients (61.5%) consented and enrolled in the study. Reasons for declining enrollment included: planning to transfer to a rheumatologist in another state, not interested and/or not ready to move to an adult rheumatologist yet. Five participants (62.5%) were retained throughout the study period. Of those retained, four (80%) completed their transition to an adult rheumatologist, with one (20%) still awaiting their first appointment. Of note, four (80%) of those retained had the opportunity to participate in a joint, video, hand-off meeting between the pediatric and adult rheumatologists during their final pediatric appointment. There were zero no-show appointments among participants after they entered the study.

Baseline demographic characteristics of the pilot cohort are shown in Table 1. This includes all participants who were enrolled in the study, including those who did not complete the pilot. The mean age at recruitment was 19.5 years (SD: 1.5). Most participants were female and Caucasian, and the most common diagnosis was systemic lupus erythematosus. The majority had access to a personal source of transportation and were commercially insured.

Changes in transition readiness were analyzed using data from participants who completed both initial and final TRAs (n = 4), shown in Table 2. For participants who completed both surveys, the overall scores for transition self-confidence as well as self-management skills (managing health and navigating health care) increased, even while the perceived importance of transition decreased slightly. The greatest improvement was observed for using/navigating health care, with a group mean increase from 8.8 to 11.5 points, and an average individual improvement of 2.8 points (SD: 3.8). Only one participant's score did not change, though notably this individual had a near-perfect score across all domains. The specific sub-domains that appeared to have the greatest mean score increases were making doctors' appointments and having a copy of my current plan of care (mean change +50.0%, n = 4). Two sub-domains—knowing what to do in a medical emergency and knowing how to fill out medical forms—were the only ones that showed a score decrease (mean change -25.0%, n = 4).

Figure 2. Study Inclusion

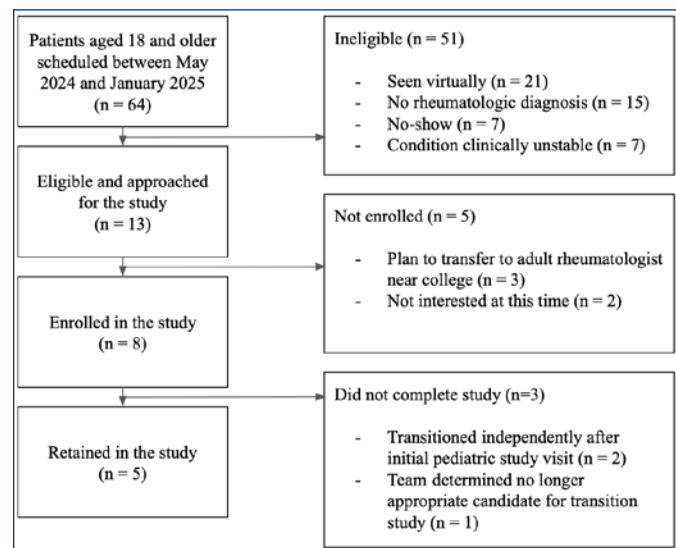


Table 1. Baseline Participant Demographics (n = 8)

Characteristic/Demographics	n or Mean (SD)
Gender	
Male	2
Female	6
Age	19.5 (1.5)
Race/ethnicity	
Native American/Alaska Native	0
Asian	1
Black/African American	0
Hispanic/Latino	2
Native Hawaiian or Pacific Islander	0
White/Caucasian	5
Primary Rheumatic Diagnosis	
Juvenile Idiopathic Arthritis	1
Systemic Lupus Erythematosus	2
Discoid Lupus	1
Gout	1
Mixed Connective Tissue Disease	1
Raynaud's Phenomenon	1
Immune Dysregulation	1
Insurance Type	
Public	3
Private/Commercial	5
Personal Source of Transportation	
Yes	7
No	1

Table 2. Initial and Final Transition Readiness Assessment Scores (n = 4)

	Visit or Score change	Importance (0-10)	Confidence (0-10)	Managing Health (0-9)*	Navigating Health Care (0-14)*
Overall Mean (SD)	Initial	7.0 (4.7)	5.5 (4.4)	7.3 (2.1)	8.8 (5.1)
	Final	6.8 (4.6)	6.0 (4.6)	8.3 (1.5)	11.5 (2.1)
Mean change	N/A	-0.2	+0.5	+1.0	+2.7
Mean individual change (SD)	N/A	-0.3 (0.5)	+0.5 (0.6)	+1.0 (2.0)	+2.8 (3.8)

* Complete survey questions/domains are shown in Appendix B. TRA response options were as follows: 1) I know this; 2) I need help with this; and 3) Someone needs to do this...(Who?). Each question that was answered using option one was given one point, while options two and three were given zero points.

DISCUSSION

This is the first study in Rhode Island that has been undertaken to improve the transition from pediatric to adult care in rheumatology. While systematized pediatric to adult HCT has started to be implemented in other settings in Rhode Island, such as primary care and pulmonology, to our knowledge, this study has been the first to incorporate a warm hand-off using video. Overall, while the transition pilot study did not meet our target sample size of 10–15 participants, it did meet all feasibility goals, evidenced by 61.5% recruitment rate, 62.5% retention rate, and 80% completion of joint video visits. Most notably, there were zero no-show appointments among participants after they entered the study. It is possible that discussion of the transition process allowed patients and their families to become more engaged in their care overall. Patients, their parents/guardians, and clinicians all verbalized appreciation for having a systematized process for moving patients from one system to another within Rhode Island's "really confusing" (Parent 1) healthcare landscape. At our institution, Got Transition[®] helped provide a foundational toolkit that was able to be adopted by our system. The bidirectional communication that resulted from adopting this framework, particularly our choice to implement a video hand-off call between the patient and the pediatric and adult rheumatologists, was especially well-received by all parties involved.

Baseline transition readiness scores in this pilot cohort were generally high. Other studies have noted that transition importance and confidence scores tend to increase as patients move from age 12 to 26,⁸ therefore the high overall scores might be attributable to the age group chosen for the pilot (at least 18 years of age). Given that two participants in our cohort dropped out after the first visit to manage their transition independently, the intervention may be too long for certain young adults. Thus, future iterations of similar programs should be tailored to patients' individual needs.

While most patients felt that moving to an adult rheumatologist before age 22 was important, they reported slightly less confidence in their ability to do so. We suspect this could be due to participants' concerns about "getting used to

a new doctor" (Participant 4), and perceptions that "pediatric doctors listen better and take their time" (Participant 2). Most participants reported knowing their health needs and being able to explain them to others. Initial knowledge regarding navigating healthcare, such as getting referrals to other providers, was more mixed. Specifically, "[having] trouble making appointments over the phone" (Participant 2) was cited as a barrier, which could be attributed to generation-based preferences for virtual over phone-based scheduling options.⁹ Nevertheless, this domain showed the greatest mean growth among participants retained in the study, with a 2.8-point average individual increase. Interestingly, while several participants' scores were stagnant for transition importance and confidence, two participants' (Participants 3 and 4) scores increased for navigating healthcare. This finding suggests that a structured HCT program such as this one could help develop patients' navigation skills, even if their confidence and self-perceived importance of transition do not change. Final TRA results from several participants across multiple visits, however, do not suggest a substantial change in transition readiness between appointments. It is possible that the limited time course of this study, one year, and the nature of the intervention, education provided within pre-existing appointment slots, as opposed to intensive educational sessions outside of regular appointments, were not sufficient to induce large changes in transition readiness.

As part of our program, adult rheumatologists were provided with detailed verbal and written patient summaries, as well as information regarding the nuances of conditions such as juvenile idiopathic arthritis and childhood-onset systemic lupus erythematosus. This information was finite in scope to accommodate the limited time in adult rheumatologists' schedules and the pilot nature of this study. However, in the future, more comprehensive education is needed for adult clinicians to welcome these patients into their practices. Increasingly, studies have called for integration of transition training within undergraduate and graduate medical education to best support the biomedical and psychosocial needs of young adults with medical complexity. Additionally, the next steps would be to reach out to/include federal agencies and philanthropic organizations to support formal transition-related training for adult physicians.¹⁰

Limitations

There were several limitations to this study, most notably the small sample size. Recruitment was challenging given the rarity of childhood rheumatic diseases and the transient nature of this population, adults aged 18 to 25, many of whom moved back and forth for college. Moreover, a significant number (n = 21) of patients 18 and older were only seen

virtually during the recruitment timeframe. Evidence from the literature suggests that young adults tend to prefer telehealth over in-person visits,¹¹ therefore, recruitment might be more successful in this population if incorporated using virtual modalities.

The multi-system nature of patients' rheumatologic conditions presented challenges as well. While transfer to additional specialties (i.e., nephrology, hematology) was out of scope for this project, patients and families mentioned that participation in the study helped demystify pediatric-to-adult transition. Additionally, it prompted them to consider discussing the move to an adult clinician with their non-rheumatology pediatric specialists. However, many families discussed the dearth of adult specialists, particularly primary care clinicians, as the primary barrier to transitioning to adult care in Rhode Island. Ultimately, larger systemic change is needed to bring more adult and pediatric physicians, as well as advanced practice practitioners, to Rhode Island.

Additionally, TRA survey data included three responses: 1) I know this; 2) I need help with this; and 3) Someone needs to do this...(Who?). Patients would sometimes choose "Someone needs to do this...(Who?)" while not choosing "I know this" or "I need help with this." This response did not necessarily provide a good assessment of where the patient was at or their readiness when our goal was to increase patient autonomy and self-assessment of their skills. This was a limitation of the survey, as it ultimately did not provide a clear understanding of their transition readiness. In future iterations, we would recommend delving further into discussion regarding these responses, and whether they should be included.

Lastly, time proved a significant barrier to the long-term success and sustainability of this process. The pediatric rheumatologist was allotted 15 minutes for follow-up appointments, which was an insufficient amount of time to discuss both the patient's medical needs and the transition. While the research team took additional time (if needed) immediately following the patient's appointment to discuss transition-related topics, it is unlikely that the pediatric rheumatologist will be able to cover this information without additional staff support and/or scheduled, billable appointment time with relevant current procedural terminology (CPT) codes (i.e., 96160, 99451, etc.)¹² in the future. Time for video exchanges with adult rheumatologists also proved challenging. The adult rheumatologists blocked off 10-15 minute time slots in their schedules to meet with the pediatric rheumatologist and patient via video; however, this did not count as a billable appointment in their schedules. Given the small number of study participants, clinicians expressed that the method was manageable. However, this model might be more difficult to implement in a larger cohort without structural policy changes, such as value-based payment models. Promisingly, Rhode Island has

recently begun to lead efforts in this area. For example, in early 2026, Rhode Island Medicaid intends to compensate for several transition-related services as part of Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Benefit.¹³ Ultimately, continued investment in such work is needed to support transition sustainability.

CONCLUSION

In summary, this pilot rheumatology transition program using the core elements from Got Transition[®] demonstrated preliminary feasibility and high acceptability, with notable success incorporating warm hand-offs utilizing video. Our goal is that the program will be expanded to include a larger cohort of rheumatology patients in the coming years, in order to best assess the needs of this population. We also hope this model can be applied to other specialty clinics that treat patients with complex chronic illnesses, and do not currently have a systematized transition program.

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