Paediatric-to-adult transition experience in vasculitis: report of a model of care and outcomes

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Abstract

Objective

Transitioning from paediatric to adult care can be challenging. Whereas transition models of care have been shared in some rheumatological conditions, reported experience in vasculitis is lacking.

Methods

Retrospective chart review of adolescents aged 16-18 years assessed at the vasculitis transition clinic by paediatric and adult rheumatologists, and then scheduled for follow-up at the Adult Vasculitis Clinic (Toronto, Canada) from January 2013 until May 2020.

Results

Twenty-eight patients were seen at the transition clinic and included. Mean age at transition was 17 years and 11 (± SD 2) months, with a mean follow up from diagnosis of 32 (± 24) months. Most patients had ANCA-associated vasculitis (n=19, 39%), followed by Takayasu's arteritis (n=4, 14%); all but one were in remission at the time of transition. Twenty-six (93%) patients showed up for their first booked adult visit (two did not, were called and rebooked), after a mean of 4 (±2) months after transition clinic. Subsequently, two patients missed 1 appointment, and three missed ≥ 2 appointments; only one (4%) stopped coming, while in remission for >2 years post-transition. Five (18%) patients were identified to have medication non-adherence after transition. With a mean follow up post-transition of 32 (±25) months, 7 (25%) patients had minor and five (18%) had major relapses, at a mean of 17 (±9) and 25 (±15) months post-transition, respectively (compared to 12 (43%) and 9 (32%) prior to transition). At their last visit, all were in remission, 18 (64%) off glucocorticoids, and damage had remained stable.

Conclusion

This model of care of vasculitis transition clinic resulted in favourable outcomes, as reflected by continuity of follow-up, and no increased risk of relapse.

Key words
vasculitis, health care transition, model of care

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Received on November 9, 2021; accepted in revised form on January 19, 2022.

Competing interests: C. Pagnoux reports receiving fees for serving on advisory boards from Chemocentryx, Otsuka, GlaxoSmithKline, Sanofi, AstraZeneca and Hoffman-La Roche; he also reports lecture fees and research grant support from GlaxoSmithKline, Hoffman-La Roche, Pfizer, Amgen and TEVA. The other authors have declared no competing interests.

Introduction

The transition from childhood to young adolescence and ultimately adulthood represent critical periods in terms of physical, psychosocial, and emotional development and maturity. Children with chronic health conditions experience an added challenge of having to endure the demands and responsibilities of having to carry these diseases with them through adulthood, and have continued follow up and care. Ensuring a smooth process of shifting from paediatric to adult care constitutes a key component of this transition, to optimise disease outcomes on the long term.

The development of health care transition (HCT) models and clinics has been an area of increasing interest over the past decade, with efforts to implement practice guidelines, create readiness assessment tools, and define successful transition outcome measures. Studies have been conducted on HCT in many diseases (1-5), including juvenile idiopathic arthritis (6-14) or lupus (15, 16), but not yet in vasculitis to our knowledge. In this article, we report on our transition model of care and clinical experience in young patients with vasculitis, and describe elements of success, pitfalls, and outcomes.

Patients and methods

We performed a retrospective chart review of all patients aged 16-18 years of age seen at the vasculitis transition clinic at Sick Kids Hospital from January 2013, when this transition clinic was initiated, until May 2020, and then scheduled to be seen for follow-up at the adult vasculitis clinic at Mount Sinai Hospital (both in Toronto, Canada). The transition clinics have been held every 6 months on average, and are led by a team of paediatricians (rheumatology and, when indicated, nephrology and/or respirology) and adult (rheumatology) physicians with expertise in vasculitis, fellow residents, and a coordinator nurse. A social worker and pharmacist are also involved, as needed. A few months up to a couple of years before the transition visit, all concepts of the transition process are gradually introduced by the paediatricians and discussed with the adolescent and the parents. Just prior to the transition visits, a paediatric physician and/or fellow draft(s) a detailed transition letter, including a summary of diagnosis and disease course, the various treatment decisions made, and social aspects of care. During the transition visit, the medical history of patients is thoroughly reviewed, and a future care plan is devised, combining the expertise of the paediatric and adult teams. The families/caregivers and patients are informed of the agreed plan, and counselled about what course to expect, as they progress into adulthood. Need for referrals to other subspecialties (*e.g.* neurology, psychiatry or respirology) are also discussed. At the end of the visit, patients are given a "graduation" certificate from Sick Kids to celebrate the milestone, along with the contact information and the date for their first appointment at the adult vasculitis clinic (if the patient is felt to have active disease at the time of the transition clinic, transfer and the first adult visit are delayed until the patient is stable enough and/or in clinical remission). When timely feasible, the patients and parents are ushered to the adult clinic (located across the street), and meet and greet the administrative staff members. After the visit, the detailed transition letter is finalised, and sent to the adult vasculitis and family physician, along with copies of important blood test results, biopsy and imaging reports. The adult vasculitis physician also starts application(s) as needed, to ensure that access and coverage of medication(s) such as biologics past 18 years old are sorted out, in order to prevent any breaks in treatment. At the first adult visit, the patients (and families, if still attending) meet the same adult vasculitis physician encountered at the transition clinic.

For this study, main patients' demographics, disease characteristics, and treatments prior to, at, and after transition were analysed. The number of missed appointments after transition were recorded, as well as loss-of-follow up, medication adherence after transition (as acknowledged by the patients, spontaneously or after asking), educational and/or work status. Remis-

sion and relapses were defined as per the EUVAS/EULAR recommendations (17). Disease activity was assessed using the Birmingham activity score (BVAS, version 3) at the time of transition, throughout subsequent follow up, and on the last adult visit. The vasculitis damage index (VDI) was recorded at the transition and last adult visits.

The study was approved by the Mount Sinai Hospital Research Ethics Board (20-0240-C), and patients consented for their clinical data to be used for the purpose of this research.

Results

A total of 28 patients were seen at the transition clinic between 2013 and 2020, and were included in this analysis. Main demographics and clinical data are summarised in Table I. The majority of patients were female (n=20, 71%), mostly Asian (n=14, 50%) or white (n=11, 39%). Most of the patients (n=19, 68%) had ANCA-associated vasculitides (12 granulomatosis with polyangiitis (GPA), 3 microscopic polyangiitis (MPA), 2 eosinophilic granulomatosis with polyangiitis (EGPA), and 2 renal-limited vasculitis); 4 (14%) had Takayasu's arteritis (TAK); and the remaining 5 had Behçet's disease, IgA vasculitis, cutaneous polyarteritis nodosa, or deficiency of adenosine deaminase 2.

At the time of the transition clinic visit, mean age of patients was 17 years and 11 months (± standard deviation SD, 2 months), and mean duration of disease since diagnosis was 55 months (±43; median, 48 months [interquartiles IQR, 21-79]). The mean cumulative dose of glucocorticoids prior to transition was 20402 (±41,731) mg (median, 9513 mg [IQR, 6694-18850]), with a mean duration of glucocorticoid use prior to transition of 32 (±31) months (median, 22 months [IQR, 13-38]). All but one patient were in remission (BVAS=0) at the time of transition, and 15 (54%) were still on glucocorticoids. Three were off both glucocorticoids and other immunosuppressive therapies.

All but two patients (93%) showed up at their first booked adult visit appointment; the two patients who did not show were called, rescheduled, and eventually came for a follow-up visit.

Table I. Main patient demographics and diagnoses.

Parameter	Value
Age at transition clinic visit, mean (± SD)	17 years, 11 months (± 2 months)
Female, n (%)	20 (71 %)
Ethnicity, n (%)	
Asian	14 (50%)
White	11 (39%)
Other	3 (11%)
Aboriginal	1
Congolese	1
Guyanese	1
Vasculitis diagnosis, n (%)	
ANCA-vasculitis	19 (68%)
Granulomatosis with polyangiitis	12
Microscopic polyangiitis	3
Eosinophilic granulomatosis with polyangiitis	2
Renal-limited vasculitis	2
Takayasu arteritis	4 (14%)
Other	5 (18%)
Behçet's disease	2
IgA vasculitis	1
Cutaneous polyarteritis nodosa	1
Deficit in adenosine deaminase 2	1
Educational status at transition clinic visit, n (%)	
Grade 12, high school	7 (25%)
College/university	19 (68%)
Job (paid)	2 (7%)
Time from transition clinic visit to 1st booked adult visit, mean (± SD)	4 (± 2) months
Distance (kilometres) from home to adult vasculitis clinic, mean (± SD)	50 (± 48) km
Patients living <50 km	20 (71%)
Patients living ≥50 km	8 (29%)

ANCA: anti-neutrophil cytoplasm antibody.

Patients were seen in the adult vasculitis clinic after a mean of 4 (±2) months from the transition visits.

The mean duration of follow up post-transition was 32 (±25) months (median, 30 [IQR, 12-47]). All but one patient continued to regularly attend their appointments; one stopped coming while in remission for >2 years post-transition, and five (18%) missed some follow-up clinic appointments at any given time (2 patients missed 1 appointment; 3 patients missed 2; and 1 missed 3; all these "no shows" were rescheduled). Non-adherence to medication at any given point was identified in 5 (18%) patients, such as a lower intake of azathioprine (in a patient with GPA, who admitted having taken only 50 mg three to five times per weeks, instead of daily for a while, even before the transition; or in a patient with TAK who missed a few infliximab infusions before and after transition).

Prior to transition, 12 (43%) patients had minor and 9 (32%) had major relapses, compared to 7 (25%) and 5 (18%) post-transition, at a mean of 17 (± 9) and 25 (± 15) months after transition, respectively (Table II) (18). All patients were in remission at their last adult follow-up visit, with 18 (64%) of them being off glucocorticoids, for a mean duration of 25 (± 19) months. Two of the 3 patients who were off therapy at the time of transition had remained so, while one was put back on azathioprine and glucocorticoids after a minor relapse 2 years post-transition. All patients maintained an unchanged VDI (1.04 ± 1.55), similar to that of the transition clinic visits.

At the time of transition, 7 (25%) patients were in high school, 19 (68%) patients had just started University or College, and 2 (7%) were working. For those 16 patients for whom information on study or work status was collected at their last follow-up adult visit, none had dropped out of school or College, and some had graduated, one changed his major, and one electively

Table II. Detailed treatments received, number of minor and major relapses, prior to and after the transition to adult vasculitis clinic.

Diagnosis	Patient #	Treatment					Number of relapses		
		Prior to transition (ever)	At transition		At last follow up visit		Prior to transition		After transition	
			IS therapy	PDN daily dose	IS therapy	PDN daily dose	Minor	Major	Minor	Major
GPA	1	IV MP, PDN, RTX, PLEX	RTX	5 mg	RTX	5 mg	0	0	0	0
	2	IV MP, PDN, CYC, PLEX, AZA	AZA	-	RTX	-	1	0	2	1
	3	IV MP, PDN, CYC, PLEX, AZA, RTX	RTX	-	RTX	-	0	1	0	0
	4	CYC, PDN, MMF, MTX, RTX	RTX	-	RTX	-	1	1	0	0
	5	RTX, PDN, PLEX	RTX	5 mg	RTX					
	-	0	0	0	0					
	6	IV MP, PDN, CYC, RTX, IVIG, MTX	RTX, MTX	-	RTX, MTX	-	3	1	0	1
	7	PDN, RTX, MTX, AZA	RTX, AZA	15 mg	-	-	2	0	1	0
	8	IV MP, PDN, CYC, AZA	-	-	AZA	-	0	0	1	0
	9	IV MP, PDN, CYC, RTX, PLEX, AZA, MTX	AZA	-	AZA	-	2	3	0	0
	10	CYC, PDN, AZA	-	-	-	-	1	0	0	0
	11	IV MP, PDN, RTX, PLEX, IVIG	RTX	5 mg	RTX	5 mg	0	0	0	0
	12	PDN, CYC, RTX, MMF, MTX, eculizumab, IVIG	MTX, LFN, RTX, IVIG	20 mg	RTX*	-	1	4	0	0
MPA	13	CYC, PDN, AZA	AZA	5 mg	AZA	-	0	0	0	0
	14	CYC, PDN, MTX, AZA, RTX, IVIG, HCQ	RTX, IVIG, HCQ	-	RTX, IVIG	-	1	6	0	0
	15	IV MP, PDN, RTX	RTX	7.5 mg	RTX	5 mg	1	1	0	0
EGPA	16	CYC, PDN, AZA	AZA	5 mg	AZA	5 mg	1	0	0	0
	17	PDN, AZA, omalizumab	AZA, omalizumab	5 mg	AZA, benrali-zumab	5 mg	0	0	1	1
Renal-limited ANCA vasculitis	18	IV MP, PDN, CYC, AZA	-	-	-	-	0	0	0	0
	19	IV MP, PDN, CYC, PLEX, AZA	AZA	5 mg	AZA**	5 mg	0	0	1	0
TAK	20	Infliximab, PDN, MTX	Infliximab, MTX	40 mg	Infliximab, LFN	7.5 mg	0	0	2	1
	21	PDN, CYC, AZA, infliximab	AZA, infliximab	7.5 mg	AZA	-	0	1	0	0
	22	IV MP, PDN, MTX, infliximab	MTX, infliximab	12.5 mg	MTX, infliximab	5 mg	0	0	0	0
	23	IV MP, PDN, MTX, infliximab, IVIG	MTX, infliximab	5 mg	MTX, infliximab	5 mg	0	1	0	0
Behçet's disease	24	PDN, colchicine, AZA	AZA, colchicine	-	AZA, colchicine	-	1	0	2	0
	25	IV MP, PDN, AZA	AZA	10 mg	AZA	5 mg	0	0	0	0
IgA vasculitis	26	MTX	MTX	-	AZA	-	0	0	1	0
Cutaneous PAN	27	PDN, colchicine, MTX	MTX, colchicine	-	colchicine	-	7	0	0	0
DADA2	28	PDN, MTX, colchicine, etanercept	etanercept	-	etanercept	-	0	0	0	0

AZA: azathioprine; CYC: cyclophosphamide; DADA2: deficiency of adenosine deaminase 2; EGPA: eosinophilic granulomatosis with polyangiitis; GPA: granulomatosis with polyangiitis; INX: infliximab; IS: immunosuppressive (therapy); IVIG: intravenous immunoglobulins; LFN: leflunomide; MMF: mycophenolate mofetil; MP: methylprednisolone; MPA: microscopic polyangiitis; MTX: methotrexate; PAN: polyarteritis nodosa; PDN: prednisone; PLEX: plasmapheresis; RTX: rituximab; TAK: Takayasu's arteritis.
*received eculizumab one dose, a few month prior to transition, then oral avacopan, post-transition and for 3 years (18).
**received RTX for induction (1g x 2), followed by maintenance with AZA (RTX was not approved for maintenance).

stopped working after having successfully given birth to a healthy baby (via caesarean section, at 41 weeks).

Discussion

The vasculitis transition clinic in Toronto was established in 2013 to facilitate and ensure a smooth continuation of care, and limit the risks of disease flares or treatment breaks. This first evaluation of the model of care showed favourable outcomes, as reflected by the high continuity of follow up, and the absence of an increase in the relapse rates in the months following transition.

Over the past years, HCT has been an area of great interest with many efforts directed towards establishing guidelines to assist clinicians caring for transitioning young patients (19-26). Although data are lacking in vasculitis patients, experience of HCT in other conditions, especially rheumatological ones, should be easy to adapt and use for vasculitis (25). The American Academy of Paediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians (ACP) published definitions and principles of transition health (27), globally concordant with the EULAR/PReS recommendations (28), as well as the National Institute for Health and Care Excellence (NICE) quality statements in the UK (29). Similar initiatives have been developed in Canada in other subspecialties (25).

However, the literature is not yet clear about what truly defines a successful HCT (30). In a Delphi study with an international panel of 37 experts, "assuring a good coordination between paediatric and adult professionals" and the number of "patient[s] not lost to follow-up" reached the greatest agree-

ment level (97% and 91%, respectively) to define success (31). In a Canadian study in patients with JIA, the "lack of success", rather than success, was used as an outcome, and was defined as the failure to make initial contact with an adult rheumatologist, or to continue to follow-up with an adult rheumatologist two years after transfer. In that study, 52% of patients had such an "unsuccessful transfer" (32), whereas results were better in some other studies (33). In our study, none of the patients with vasculitis was lost after the transition clinic, and only one patient with cutaneous PAN stopped coming after two years in remission post-transition.

The requirements to achieve success remain to be fully determined. In a study of 1,623 patients with 6 different chronic (non-vasculitis) conditions, including lupus, and undergoing transition, a successful HCT was associated with a lower median number of days between the last paediatric and first adult visits (34), which was around 4 months in our model. The appropriate timing of the transition, when the patients and families are ready, along with sound explanation around the meaning of the transition are other important aspects of success. In a recent survey among 65 members of the Canadian Rheumatology Association (CRA) (35), the timing of transfer reported by 85.7% of respondents was between the ages of 16–18 years, in keeping with our study findings. An early preparation to facilitate the planning of the transition and the patient's engagement are helpful, along with efforts to clarify expectations (25). The Six Core Elements of *Got Transition®*, a US-based, federally funded resource "to improve transition from paediatric to adult-health care through the use of evidence-based driven strategies" are "establishing a transition and care policy/guide, tracking and monitoring progress, administering transition readiness, planning for adult care, transferring to an adult clinician, and confirming completion of transfer" (36). Most of these elements have been fulfilled by our model of care, but we have not prospectively used any measurable tracking methods, or tools to assess readiness. A few readiness assessment tools have been developed and published, mostly since mid-2010s, such as the Readiness for Adult Care in Rheumatology (RACER) (37) for patients with JIA, or the Transition Readiness Assessment Questionnaire (TRAQ) (38), and revised Am I ON TRAC for Adult Care questionnaire (25, 39-42).

Supplying the optimal environment, training, and resources are other key factors for success (43, 44). The nurse coordinator at our clinic played a critical role, being at the core of the logistical organisation and for communication with patients and their families. Additional support from psychologist, social worker, and/or pharmacist can be required, especially when there is a switch to different policies for drug coverage from children to adults. Engagement of both paediatric and adult clinicians, education, and training opportunities on HCT are other crucial elements (45). Most rheumatologists are still not familiar with existing resources and practice recommendations on HCT (46, 47).

Along with the development of a relationship with the adult provider focused on their personal goals, the main concern from patients' perspective (obviously shared with physicians) is maintaining stability of the disease (48-50). Some studies raised concerns that morbidity and mortality increase following HCT (33). Hersh *et al*. reported that almost 30% of the patients with various chronic rheumatological conditions had an increase in disease activity after transfer (51). However, in a larger administrative study conducted in the USA between 2012 and 2014, on 30,269 hospital discharges of youth with rheumatic diseases categorised as pre-transitional (age, 11–17 years old), transitional (age, 18–24) or post-transitional (age, 25–31), transitional age was not found to be a risk factor for inpatient mortality (52), whereas a diagnosis of vasculitis was. While some of our study patients had severe and/or relapsing diseases, including one with refractory GPA and recurrent subglottic and bronchial stenoses, none died or developed any further damage after transition. Relapses are common in patients with childhood-onset vasculitis, possibly more than in patient with adult-onset vasculitis, especially AAV (53) or PAN (54). However, the number of relapses did not increase post-transition, with most of the observed flares having occurred more than a year after transition.

Conclusion

A good, "successful" HCT relies on the understanding of its multi-dimensional, interconnected aspects. The model of care in our vasculitis transition clinic resulted in favourable outcomes, but its sustainability requires continuous efforts from all participants, along with institutional and funding support. Acknowledging and facilitating the teamwork efforts are fundamental elements. The implementation of validated tools to assess readiness for transition and measure quality of care may further improve the model, and demonstrate its added value. Randomised controlled trials to study models of HCT might also add evidence for their respective efficacies, in various settings.

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