



JUVENILE IDIOPATHIC ARTHRITIS (JIA) TRANSITIONAL CARE SYSTEMS REQUIRE REVISION TO IMPROVE PATIENT OUTCOMES: OPINION REVIEW

JIWON HWANG[1], JUSTIN PHUNG[1], SARAH SADAFI[1], SABRINA SEFTON[1], AMELIA WILSON[1]

[1] BACHELOR OF HEALTH SCIENCES (HONOURS), CHILD HEALTH SPECIALIZATION, MCMASTER UNIVERSITY

ABSTRACT

Juvenile Idiopathic Arthritis (JIA), encompassing a class of arthritis for which there is no known origin, is the most common chronic inflammatory rheumatic condition arising during childhood. It is associated with a diverse host of complications resulting from immune and growth dysregulation characteristic of JIA pathogenesis. Past evidence has shown that care of JIA patients as they transition into adulthood — whether it be psychological, rheumatological, etc. — has been significantly and systemically overlooked. Patients have reported feeling increasingly overwhelmed, unprepared, and dismissed during this time of care. Therefore, improving pediatric patients' experiences, as they navigate transition readiness into the adult healthcare system is a prevalent issue. This report aims to provide evidence on JIA-specific institutional barriers to a successful transitional care experience into adulthood in multiple comparator jurisdictions. This investigation, which analyzed both qualitative and quantitative evidence, revealed that major obstructions to constructive transitional care experiences include: flaws in JIA classification and diagnosis, lack of critical skill building pre-transition, insufficient patient education on their condition, and absence of adult healthcare provider support post-transition. Despite major limitations existing within transitional care provision, there are a variety of successful frameworks that warrant more attention and analysis. Consequently, future directions should focus on these effective models for guidance in order to improve transitional care resources and services, and better support JIA patients.

INTRODUCTION

Juvenile Idiopathic Arthritis (JIA) is the most common paediatric haematological disorder(1), and affects 3 million youth globally per year (2). Its etiology is relatively unknown beyond that it arises through a combination of genetic and environmental factors (1). JIA is classified by six different subtypes according to the International League of Associations for Rheumatology (ILAR) criteria: oligoarticular, polyarticular (pJIA), systemic (sJIA), psoriatic, enthesitis-related (ERA), and undifferentiated arthritis (1). Each subtype differs in the type of joint affected, genetic predisposition, laboratory markers, presence of rheumatoid factor (RF), and systemic manifestation (1).

Both JIA and rheumatoid arthritis (RA) are classified as autoimmune diseases characterised by joint pathology. Through extensive genotype analysis, Hinks et al. noted that both JIA and RA shared an association with human leukocyte antigen-DRB1 amino acid at position 13, revealing potential genetic links between the two conditions. An article by Brigham and Women's Hospital also cited similarities, specifically regarding the HLA locus on chromosome 6 (3,4). Lastly, physicians often rely on similar combinations of medication and lifestyle modifications when approaching clinical treatment for JIA and RA (1,5). For example, disease modifying antirheumatic drugs (DMARDs) — corticosteroids for joint pain and inflammation management — are typically administered in conjunction with strength-building and pro-mobility physical therapy, for both JIA and RA patients (1,5). However, there are also numerous key differences between JIA and RA regarding symptomatology, prognosis, and approach to care. While JIA is characterised by several subtypes, RA is viewed more homogeneously (6). Additionally, given that JIA is

diagnosed in patients 16 years old and under, JIA may affect a child's long-term bone development, while RA patients undergo typical bone and growth development in childhood (7). Moreover, JIA patients can experience periods of remission followed up by flare-ups as they age, while RA patients experience symptoms for the remainder of their life (7).

In addition to differences in pathogenesis between JIA and RA, there is an abundance of considerations within JIA treatment that make it challenging. For instance, the wide variety of JIA subtypes makes it difficult to compare health outcomes. Further, due to the limited scope of paediatric-focused therapeutic options, extrapolating treatment efficacy data from adult populations has been recommended to accelerate paediatric intervention development (8). However, the differing measurement endpoints between JIA and RA present difficulties in predicting similarities and differences in responses to medication between JIA and RA patients (8). Moreover, clinicians must take into account parental influences on a patient's perception of their disease status and adherence to treatment (9). A questionnaire-based study by April et al. demonstrated that guardians reported their children being more averse to and having more difficulty taking medication and doing exercises, than their children reported (9). Possible explanations for this disagreement include divergence in perception of disease circumstances between the parents or caregivers and those with lived-experience (9). Furthermore, parents tend to be more conscious of the possible negative consequences of the disease, whereas children tend to take more optimistic outlooks (9). This finding highlights the special need of child health practitioners to balance advocating for their patients' specific needs with their caregivers' needs. With these differences between JIA and RA in mind, it is important that as JIA patients transition into adulthood, they are viewed as distinct from adult-onset arthritis patients.

STRUGGLES AMONG PEDIATRIC-TO-ADULT TRANSITIONAL CARE

Transitional care refers to the planned movement of patients from one healthcare setting to another and is internationally recognized as a priority area for change within healthcare (10). Given advances in modern medical care, there exist more adolescents and young adults living with chronic diseases than ever before, pointing to a growing demographic of patients requiring transitional care as they progress to adulthood (11). The specific transition from paediatric to adult healthcare typically occurs among adolescents (aged 10-17 years) and young adults (aged 18-25 years) suffering from chronic conditions (12). This transition to adult-oriented healthcare systems can be stressful and overwhelming, extending over long and challenging points in one's life such as entrance into highschool or postsecondary education. Furthermore, much of the patient's illness management and advocacy role in paediatric care is taken on by the parent or caregiver, often leaving the

the patient unprepared to handle the increased responsibility of disease management as they transition into adulthood.¹³ Therefore, the three central goals of transitional care include^{12,13}: adequate knowledge and skill acquisition in patients, readiness of both the patient and parents, and proper communication of patient clinical history to the adult care provider, all prior to transfer.¹⁴ With respect to fulfilling all three principles, there still exist intersectional barriers to all those involved (patients, care providers, etc.) and continues to be an ongoing area for improvement in patient care.¹⁵ Therefore, the three central goals of transitional care include (12,13): adequate knowledge and skill acquisition in patients, readiness of both the patient and parents, and proper communication of patient clinical history to the adult care provider, all prior to transfer (14). With respect to fulfilling all three principles, there still exist barriers to all those involved (patients, care providers, etc.) and continues to be an ongoing area for improvement in patient care (15).

It has been reported that patients entering young adulthood with chronic childhood-onset medical conditions have worse health outcomes compared to adults who experienced adult-onset for those same medical conditions (16,17). These outcomes include increased rates of emergency room visits and hospitalizations, nonadherence to health interventions and loss to follow-up, increased difficulties in school/work, and elevated costs of care (15,16). Furthermore, studies acknowledge a high degree of variability in identification of and defining valid outcome measures such as utilization of services, coordination of service providers, cost of care, and disease outcomes, making it extremely difficult to compare the relative success or failure of a transitional program (15). There are various risk factors for poor transitional outcomes, including distance to adult specialty centres — which in some cases may be located in entirely different cities from their previous paediatric provider — social complexities such as socioeconomic status and environmental exposures, public or lack of insurance, and instability of disease prior to transfer (15,17).

Overall, issues in transitional care are deeply complex. Though some exploration has been done regarding barriers to successful transition in patients with rheumatic disease, actionable steps to facilitate the transitional process are still scarcely implemented (15). The most prevalent barriers to successful JIA transitional experiences will be further elucidated in the next section.

CHALLENGES RELATING TO JIA MISCLASSIFICATION & MISDIAGNOSIS

An existing challenge with regards to JIA patients in childhood and while transitioning into adulthood is the overlap in classification criteria with other rheumatic conditions. The diagnosis of JIA patients with a specific subtype of JIA — or even adult RA — can lead to

significant differences in patient outcomes and treatment options. The examples discussed below are not an exhaustive list.

1. Polyarticular Juvenile Arthritis (pJIA) & Rheumatoid Arthritis (RA)

pJIA is often mislabeled as RA in adult rheumatology clinics. The lack of clinical treatment knowledge can be indicated by data revealing that adult rheumatologists tend to assign a diagnosis of RA to 45% of JIA patients immediately after transition from paediatric care (18). Another study found that 92% of patients with childhood RF-positive pJIA and 57% with RF-negative pJIA were diagnosed with RA (19). This misdiagnosis leads to significant difficulties in treatment recommendations, which differ considerably between pJIA and RA. For example, administering DMARDs is more common in those with RA, while tumour necrosis factor inhibitor (TNFi) is more prevalently used in pJIA treatment (20). Ultimately, former paediatric patients, particularly the RF-negative subset, are a distinct clinical entity for whom further study is needed to determine optimal management. Adult rheumatologists would benefit from both increased familiarity with and improved defining of the JIA classification criteria to optimally care for the pJIA population (21).

2. Systemic Juvenile Arthritis (sJIA) & Adult-Onset Still's Disease (AOSD)

Misclassification is similarly seen for sJIA, which has strong similarities with AOSD. According to a Portuguese rheumatic disease registry, 92% of patients diagnosed with systemic-onset JIA as a child were classified as having AOSD in adulthood (22). The Yamaguchi criteria for AOSD diagnosis requires the presence of arthralgia (i.e. joint stiffness) for more than two weeks (23). However, the current ILAR classification criteria for sJIA highlights the presence of arthritis at presentation being mandatory (23). This diagnostic criteria leads to rule-outs in diagnoses of sJIA, especially since arthritis can appear at any time over the course of the disease — sometimes years after the onset of systemic manifestations. Considering the fact that classification criteria has a crucial impact on clinical decision, particularly for rare diseases, the authors of this study comparing sJIA and AOSD suggest revising sJIA's criteria.

3. Juvenile Spondyloarthritis (JSpA) & Spondyloarthritis (SpA)

These flaws in diagnostic criteria have also been demonstrated with ERA, a subtype of JSpA. There are key differences in clinical phenotype between JSpA and adult-onset SpA which may be attributed to changes in musculoskeletal maturation and immune system during childhood and adolescence (24). For example, peripheral arthritis and enthesitis are predominant in JSpA, while spinal arthritis is more typical in adult onset disease (24). Nevertheless, the ILAR criteria has resulted in a high proportion of patients with JSpA being classified in the

undifferentiated JIA group, with one study finding that 95% of adult patients diagnosed with ERA fulfilled the classification criteria for adult-onset SpA (25). Furthermore, there are differences in treatment based on one's diagnoses. Whilst rarely used in adult-onset SpA, local or systemic corticosteroids are sometimes used before treatment with DMARDs or TNFis in those diagnosed with JSpA. Additionally, DMARDs are more commonly used in JSpA because of the high prevalence of peripheral arthritis and enthesitis, conditions that would be less common in adults (25).

4. Push to Revise Classification Criteria

Overall, numerous studies have highlighted the overlapping diagnostic criteria across numerous arthritis disorders. In fact, one study has pushed to revise the current ILAR classification criteria, to distinguish forms of chronic arthritis typically seen only in children from the childhood counterpart of adult diseases (26). Thomas Lehman, chief of paediatric rheumatology at Hospital for Special Surgery in New York City, has stated that blanketed JIA diagnosis given to many kids with arthritis can have unintended consequences, especially if they have entered a clinical trial under the wrong classification. Lehman also added that there is “an urgent need for reassessment of the classification criteria and nomenclature to better reflect the diversity of childhood arthritis.” Moreover, Dr. Oliveira-Ramos, head of the Pediatric Rheumatology Unit at the University Hospital in Lisbon, also stated that there should be “a new classification capable of better unifying the language between paediatric and adult care” (25). Revising the classification criteria will lead to more accurate diagnoses and thus appropriate treatment regimes for JIA patients, improving the transition from pediatric to adult care.

CHALLENGES RELATING TO TRANSITION READINESS

1. Health Literacy & Independent Skill Building

A prominent change involved in the transition period is the increasing expectation of patients to be able to manage and advocate for their own care. Therefore, gaining skills in how to navigate the healthcare system is crucial for a smooth experience (13, 27-30). However, JIA patients regularly leave paediatric care with a notable lack in the advocacy and health literacy skills required to maintain their adult treatment plan (13, 27-30). This circumstance was reflected in a trial conducted by McColl et al., where 61 patients aged 14-21 years with JIA participated in a 14-item questionnaire entitled ‘Transition-Q’. Transition-Q is a well-validated tool whose outcome scores directly reflect healthcare self-management skills and is typically used as a proxy for transition readiness (13). Astoundingly, the results of this study demonstrated that the majority of patients showed insufficient transition readiness, despite being at the age in which transfer to adult care regularly occurs (13). For instance, 58.6% of patients responded “never” to “I drop

off or pick up prescriptions on my own” and “I book my own doctors’ appointments” (13). Additionally, only 52% of participants responded “always” to “I speak to the doctor instead of my parents speaking for me” (13). These responses indicate that, due to limited development of independence, adolescent patients may not feel comfortable initiating conversations with their healthcare provider, reflecting a critical deficiency in transition readiness among youth with JIA (13). Furthermore, in a patient-led qualitative study by Currie et al., youth with JIA ranging from 18 to 28 years old shared their thoughts on their experiences with the transition care process (28). Many patients reported feeling unprepared to move into adult rheumatology care, with one participant stating, “...I was really anxious, because like, I wasn’t prepared to be in...a whole new environment...it kind of felt like starting from...scratch, like from the start with a whole new doctor” (28). Ultimately self-management and independent skill development should be enforced in the transition readiness stage to improve patient experiences (13, 27-30).

2. Patient Education on Treatment Adherence

Another noteworthy barrier to conducive transitional care is the lack of education provided to JIA patients regarding their condition status (13, 27-30). It has been demonstrated that patients who are not properly educated on the severity of their condition are more likely to unsuccessfully transfer once they transition to adult care (13, 27-30). Hazel et al. exemplified this by conducting a systematic review at the Montreal Children’s Hospital (MCH), where the authors aimed to describe the proportion of patients with JIA who had experienced an unsuccessful transfer from a paediatric rheumatology team to an adult rheumatologist (27). Authors defined unsuccessful transfer, in this case, as failure to make initial contact with an adult rheumatologist, or failure to follow-up with an adult rheumatologist two years following transfer (27). The results indicated that 52% of JIA patients met the criteria for “unsuccessful transfer”, and that patients with less active disease status at the time of transfer were highly correlated with an almost three-fold risk of unsuccessful transfer of care (27). This suggests that young adults with relatively inactive JIA were not completely educated by their physician on the importance of ongoing follow-up, and consistent monitoring in case of a disease flare-up in adulthood (27). This highlights a gap in patient education that can present as a significant barrier to a successful transition and ultimately poor post-transition outcomes. Therefore patients with less severe disease status should be made aware of the possibility of active disease into adulthood, to mitigate inadequate patient education prior to transition (27).

CHALLENGES RELATING TO ADULT HEALTHCARE FRAMEWORKS

Lastly, strong communication and support from health-

care providers is crucial during a patient’s transitioning journey (13, 27-30). Healthcare practitioners play a major role in affecting a patient’s stress levels, self-perception, and self-assurance to take charge of their health during their transfer from paediatric to adult care (29-30). Often during this period, significant changes to JIA care are implemented, leaving patients confused about who to turn to for information and consolation (29-30). Furthermore, transitioning to adult care typically coincides with entrance into post-secondary school for JIA patients, representing a time of considerable neurodevelopment and increased need for mental health support from transitional care providers (13, 27-30).

In the aforementioned study by Currie et al, youth with JIA reported struggles adjusting to drastic changes in the office environment, format of adult rheumatology appointments (shorter and less frequent), and building a trusting, safe rapport with their new adult rheumatologist (29). One participant noted, “I’ve only seen this new doc - my new rheumatologist like, four to five times, because I usually go every six months. I haven’t been able to really establish a trusting, safe environment with him where we can have... similar conversations of how I would have with my previous rheumatologist.”(29). The shortened length of adult appointments, in comparison to their previous paediatric appointments, left patients feeling short-changed and unable to address their concerns (29). Additionally, JIA patients highlighted a drastic reduction in scope of care following transition compared to prior paediatric rheumatology teams consisting of allied health professionals and medical specialists (29). One participant noted, “A sudden drop in support was very jarring because it just really added to all these new responsibilities. And, you know, it was all in one appointment and then you had to outsource and all that [allied health care], so I just think that if you had more... continuity of care, it would be less... shocking, like being tossed in a cold pool”(29). Ultimately, there was a general consensus among JIA patients regarding feelings of frustration that stemmed from a perceived decrease in concern for well-being, mental health, and willingness to discuss intersectional challenges associated with JIA (29).

Therefore, mental health and support resources should be as readily accessible for JIA patients during transition and post-transition, as it was in paediatric care (29). This could reduce the consistently expressed feelings of being overwhelmed with novel rheumatology care frameworks, which reflect another prevalent barrier to successful transitional care among youth (29).

FUTURE DIRECTIONS

The staggering reality that approximately 50% of JIA patient transitions to adult rheumatology are unsuccessful emphasises the need for future research and action (31). Current recommendations for improving transitional care of JIA patients centre around promoting collaboration amongst health care providers, multidisciplinary paediatric specialist team — alongside the “specialized

clinic model” — patients followed up and treated lifelong in specialized clinics for both paediatric and adult patients (32). These models are particularly effective as they take a more gradual and consistent approach to transitional care, while considering both patient and family experiences (32).

The literature points to successful European models of transitional care, such as the widely implemented ‘United Kingdom Ready-Steady-Go program’(33). Beginning the transition process at eleven years old, the program emphasizes the empowerment of young patients in taking control of their healthcare through a collaborative approach to developing individualized transition plans (33). At the University of Turin in Italy, the two-stream model suggested by Dr. Fabrizio Bert describes a transitional care program dependent on the patient’s case complexity. In the case where the patient has presented with complex clinical and/or social conditions, they are directed toward a ‘multidisciplinary pathway’; this includes activating an ‘Interdisciplinary Transition Group’ that evaluates each patient in periodic meetings and provides personalized care planning (34).

Finally, in 2011, a clinical report from the American Academy of Pediatrics, the American College of Physicians, and the American Academy of Family Physicians outlined their suggested guidelines for physicians in supporting transitional care (31, 35). The key recommendations from this report included: beginning the transitional process at 12-14 years old (considered early adolescence), emphasizing the value of coordination amongst paediatric and adult healthcare providers, and providing opportunities for young patients to contribute to the decision-making process (31, 35). These recommendations align with successful transitional care models across the globe, providing direction for future JIA research and modifications to the transitional care of JIA patients (31, 35).

CONCLUSION

This report aims to explore the significance of transitional care for JIA patients as they progress to adulthood, highlighting institutional barriers to successful transitions. As the most common chronic inflammatory rheumatic condition arising in childhood, JIA poses a serious threat to the quality of life of both patients and their caregivers alike. As a child transitions into adulthood, they often bring with them feelings of stress, unpreparedness, and a lack of education surrounding their condition. Factors such as misclassification, lack of independent skill building, inadequate transitional care education, and misdirection from health care professionals act as potent barriers to constructive transition, and warrant further attention. Applying strategies from successful transitional care models such as the continuous caregiver model and the specialised clinic model, along with implementing recommended methods for healthcare professionals to properly navigate providing transitional care for JIA patients, may

provide future improvements for the clinical practice of JIA transitional care.

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