



Bridging the Gap: The Deficits in Transitional Care

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Between 14.8% and 18% of all youths in North America have a chronic health condition, with up to 98% of those expected to reach the age of 20.¹ Despite this fact, most sites in Canada do not possess the appropriate resources, supports, and educational opportunities required to support chronic disease patients transitioning from pediatric to adult care.² Transition is defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from child-centred to adult-oriented healthcare systems”.³ While ‘transfer’ of care refers to a single point in time, ‘transition’ spans the length of time preceding and following the actual transfer.² The key goals for a successful transition are to optimize health outcomes, increase adolescent involvement in their own care, and provide uninterrupted healthcare to the patient.^{2,4} The adolescent period involves the development of cognition, social groups, and sexuality that already poses several challenges. The addition of chronic disease management makes adolescence an especially sensitive period for this patient population that necessitates the need for a comprehensive clinical

framework. Unfortunately, at present there exists several limitations in the guidelines and practical transitional care provided to this high-risk patient population. Pediatric rheumatic disease can be used as an excellent model for demonstrating the gaps that exist, as these chronic conditions are often diagnosed young and require long-term management to prevent disease flare-up.

There is increasing evidence that supports quality transitional care as a predictor of good rheumatologic outcomes.⁵ Despite this, there continues to be reports of incomplete needs in this area. In fact, 25-75% of youth with juvenile idiopathic arthritis and other rheumatic diseases have fragmented care or are lost to follow-up during the transition to adult care.² Further, there is a tendency towards increased disease activity during this transition, with 50% of this young adult population experiencing active disease or flares at that time.⁶ These numbers are alarming given that many of these conditions pose a significant morbidity and mortality risk when not well-controlled. Even more worrisome is that many of these

statistics transcend diagnosis or even specialty.⁷ Multiple factors contribute to these figures. Namely, insufficient time to provide transition services, inadequate readiness of adolescents, lack of specialty adult care providers, and significant delays in the first adult visit have all been cited as major problems requiring attention.^{2,6}

To accomplish a successful transition of care, many factors need to be considered. Timing is an integral component of transition planning, yet no consensus has been reached regarding the optimal patient age to begin the process. American guidelines have recommended initiation of the process as early as 12 years, and that final transfer to adult care should be completed between 18 and 21.⁶ Conversely, Canadian sources have expressed that many factors beyond age should be considered when starting the transition, including patient readiness and request for transition, and disease activity.² Many pediatric rheumatology providers have reported prolonging their care due to concerns that their adolescent patients lack the requisite skills needed to transition successfully.⁸ There is an established need for clear consensus guidelines to filter these inconsistencies and optimize transitional care.

Another area of confusion has centred around which physician is responsible for overseeing transition to fruition. Historically, the pediatric rheumatologist has been the primary participant in the transition process, with the adult provider taking a less active role. Compared to pediatric rheumatologists, adult providers are less likely to have a written transition policy in their practice or to have given one much thought.² This represents a significant gap in care, given that studies have found 50% of the indicators for successful transition to focus on engagement between the patient and the adult provider.⁶ Open communication between both physicians and the patient is a critical component of the transition process that should be emphasized going forward. At present, most patients choose to prolong pediatric care due to concerns that adult doctors will be unfamiliar with their condition or medical history.⁹ Further, nearly half of adult providers have reported being dissatisfied with the information they receive from their pediatric colleagues.⁶ To alleviate both of these concerns, adult physicians should be provided with the necessary resources and encouraged to be an active participant in the transition process.

Many factors make adolescence the ideal time for flares in chronic disease. In addition to the potential for fragmented care during transition, this time period often aligns with the move to post-secondary education. The decision to move away from home might mean accepting the prospect of admission to an unfamiliar hospital. Likewise, adolescent patients experience an increased incidence of anxiety and depression during the transition period,⁶ which can lead to further withdrawal from the healthcare system at a time when they are medically vulnerable. In some, the intersection between their disease and newfound contraceptive requirements may be quite overwhelming. Clearly, an array of scenarios can morph adolescence into the perfect melting pot for disease flares. Consequently, this is an area of medicine that requires utmost attention to improve patient outcomes.

To address gaps in the transitional care framework for adolescents with chronic disease, several areas must be considered. The lack of designated funding has translated into a shortage of services, with 38.7% of Canadian rheumatologists stating that they have no transition service available in their area.² Increased financial support could alleviate these scarcities and act as a monetary incentive for physician involvement in transition. Likewise, an improved national approach to transition care is needed to supplement guidelines that currently exist. This resource should guide pediatric and adult providers through a unified model of care and should reference transition resources available in local areas. Finally, lack of patient and family education has been cited as one of the largest barriers to care.² Implementing education sessions and peer-support services could empower youth with knowledge about their condition, while easing parental reluctance to withdraw from their child's care.¹⁰ The implementation of these initiatives has the potential to transform transitional medicine for the better, an obligation that we owe to our adolescent patients.

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