

Transition of the Adolescent Patient with Rheumatic Disease: Issues to Consider

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The topic of transition of youth with childhood-onset rheumatic diseases to adult health care is increasingly important, because, most of these patients will continue to have active disease or significant sequelae of their rheumatic disease into their adult lives.

This article discusses the definitions of transition and models for providing transition care to youth and young adults with rheumatic diseases in the context of differing cultural and health care systems. Issues and questions relating to pediatric rheumatology transition programming are outlined, and a model program of pediatric rheumatology transition is presented.

Defining transition

Transition for patients with chronic diseases that have begun in childhood and persisted into adulthood means different things to different people. A useful description of this developmental phase for the patient is provided by Viner [1], who describes the process of transition from pediatric to adult health care providers as one part of a wider transition, or developmental process, in which the child moves from being a dependent child to an independent adult. The American Society for Adolescent Medicine describes transition as an active medical process, “the purposeful, planned movement of adolescents and young

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adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” [2]. Both of these definitions point out that transition involves a fluid movement in a continuum, rather than an administrative event in which the patient moves from the pediatric or adolescent clinic to the adult rheumatologist’s office.

The issues and definitions of transition may differ substantially, based on cultural background. For example, in some countries, children are considered adults at the age of 13 years; all adolescents older than 13 years are cared for by adult health care providers, and there is no tradition of adolescent medicine. In these countries, the processes and issues surrounding transition would have to be considered in a completely different context than in European or North American systems. To date, there has been little research on or discussion of how the transition from pediatric to adult rheumatology care differs between cultures.

Why is transition important for youth with rheumatic diseases?

Juvenile idiopathic arthritis (JIA), systemic lupus erythematosus (SLE), juvenile dermatomyositis (JDM), and other rheumatic diseases often continue to cause problems for patients into their adult years. Current research suggests that approximately one third of youth with JIA will continue to have active disease well into adulthood. These patients will require on-going medical treatment, and many will have significant disability [3–8]. Several additional studies that span many years and span several major therapeutic advances (such as the use of methotrexate) describe the outcomes of not-quite-comparable groups of patients (ie, patients with juvenile rheumatoid arthritis, juvenile chronic arthritis, JIA, or other entities) [9–13]. In spite of their unavoidable limitations, the results of all of these studies demonstrate the significant and life-long impact of childhood-onset arthritis. A series of studies published by Packham and Hall [9–12] examine long-term outcomes of a large, well-documented cohort of adults who had juvenile arthritis. In this group of 246 patients (mean age, 35.4 years), a large number of patients continued to have persisting pain and active disease requiring medications; functional disability, mood disturbance and unemployment were also common. Foster et al [13] reviewed 16 studies of outcome of juvenile arthritis in patients followed from 1 to more than 20 years between 1962 and 2002. Approximately one third of patients had disability as measured by Steinbrocker classification [14], and a significant number (between 10% and 45%) had persistent disease activity long into their adult lives. Foster’s own work examining the outcome of 82 adults with JIA (disease duration, median 21 years; range, 3–61 years) confirms these results and also examines the health-related quality of life of these patients using standardized patient-report questionnaires [13]. The patients had poor health-related quality of life in all physical domains as compared with healthy peers and impaired scores in social and emotional functioning. The patients had significant functional disability as measured by the

Health Assessment Questionnaire: adults aged 31 to 45 years had a mean score of 1.3, and adults older than 45 years had a mean score of 2.2. These scores suggest that, rather than diminishing as patients enter adulthood, the impact of JIA becomes more significant as patients get older.

The long-term outcome for young adults with other chronic rheumatic diseases such as SLE, JDM, and vasculitis has not been well studied. One can anticipate that virtually all youth with SLE will continue to require rheumatologic care in adulthood, and many already have significant damage from active disease in their childhood years. Recent studies have been published using the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index to determine damage in youth with childhood-onset SLE [15,16]. In three studies, most patients had accumulated significant organ system damage 3 to 5 years after onset of disease [17–19].

The long-term outcome for childhood-onset JDM has not been documented in the literature. One small review by Peloro et al [20] reviewed 16 patients seen over a 30-year period in one center. Six patients were reported to be in long-term remission of their disease, with average follow-up of 3 to 4.5 years, and six patients had disease flares requiring additional treatment. Another small review by Chalmers et al [21] in 1982 studied 18 adults an average of 18.5 years after diagnosis of JDM. The majority of the patients did well, with only three having significant residual disability. These subjects enjoyed a good level of educational and employment attainment. The impact of the JDM on patients' functional abilities or quality of life later in life has not been assessed in any large, recent patient cohorts.

Why is transition a challenge for youth with rheumatic disease?

The developmental tasks of late adolescence and early adulthood are monumental even in the best of circumstances (Box 1), and having a chronic rheumatic disease during this period complicates the trajectory. There is a risk for parental

Box 1. Developmental tasks of adolescence

- Independence and assertiveness
 - Independent health behaviors
 - Self-advocacy
- Development of peer relationships
- Focus on education, vocation
- Development of sexual identity
- Health and lifestyle

overprotection of children with a chronic disease, and this protection may frustrate the adolescent's pursuit of independence and ultimately self-advocacy. The inability to participate fully in usual activities (eg, sports, shopping, parties) may further isolate youth with rheumatic disease and delay development of effective peer relationships and supports that are integral to gaining independence from parents. Adolescents with rheumatic disease may not receive adequate or timely counseling about important issues such as sexual health [22].

Inevitably, youth who have had chronic rheumatic disease throughout childhood become weary of the constant intrusion of medications, doctors appointments, and the continual feeling of being different from peers, and they often reject their treatments. They may become severely noncompliant with medications and appointments and also may engage in risk-taking behaviors that pose a danger to their health (eg, a patient taking methotrexate who binge drinks with friends). By 18 years of age, at the latest, most of these grown-up children will need to make the transition to adult-oriented health services. This transition is recognized as a period of high risk for dropping out of the health care system [23]; therefore an attempt to impose a strict time of transfer to adult health care during this period increases the risk that the patient will develop a severe disease flare or complications.

What is the current availability of transition programming in pediatric rheumatology clinics? What barriers exist to providing transition services?

The level of transition programming in pediatric rheumatology clinics is variable and depends on many factors that often are related to the local health care system and health care funding. Informal survey of North American pediatric rheumatologists at meetings and through Internet discussions reveals no standard approach to transition issues and considerable variability in practice. Commonly expressed barriers to developing transition programming are funding, staff, and resources.

The British Pediatric Rheumatology Group, led by J. E. McDonagh and colleagues [24,25], has studied the issues around adolescent rheumatology care in the United Kingdom through an extensive series of surveys of various health care providers, patients, and parents. They reported that 18% of rheumatology units in the UK treating children with rheumatic diseases had a dedicated adolescent treatment unit [25]. Many health professionals, however, reported low level of comfort in dealing with the issues of suicidal risk, sexual health screening, drug use, risk-taking behaviors, and psychiatric complaints. Barriers to providing adolescent-oriented care were lack of adolescent teaching materials, inadequate clinic time, and limited training in dealing with adolescent issues [26]. Lack of integration among service providers (between regional and local hospitals and among health providers, social services, and community services) was cited as a significant barrier as well.

Barriers to well-integrated transition can be related to issues involving the patient, the family, the pediatric rheumatologist and team, or the adult rheumatologist (Box 2) [1,26]. These issues are not rheumatology-specific; similar difficulties are found in transitioning youth with other chronic illnesses such as diabetes [22] and cystic fibrosis [27].

Box 2. Barriers to successful transition for youth with rheumatic disease

Patient-related

- Burn out
- Poor adherence
- Limited knowledge about disease and treatments
- Limited insight about long-term impact of poor adherence
- Inadequate self-advocacy skills
- Reluctance to leave known and trusted staff

Parent-related

- Reluctance to relinquish control
- Reluctance to leave known and trusted staff

System-related

- Gaps in health care financing as patient moves through education and early career
- Lack of appropriate health care services for youth
- Difficulty in providing smooth transfer of records between old and new care providers

Pediatric providers

- Difficulty in 'letting go'
- Limited options for adult rheumatology care

Adult providers

- Limited knowledge of childhood onset rheumatic disease, outcomes, and adolescent developmental trajectory
- Inadequate coordination or support for these complex patients
- Limited availability of multiple service providers

Models of transition

There are relatively few well-described models for transition of pediatric rheumatology patients into adult rheumatology care, and there are virtually no data of the process of transition for these patients. Sawyer and colleagues [28] describe three general models for transition care for adolescents with chronic illness: (1) disease-focused transition from pediatric care to an adult subspecialist, (2) primary care-coordinated care spanning adolescent to adult care, and (3) generic adolescent health services, with care coordinated by adolescent care providers. In practical terms, a primary care-based model is not generally feasible because of the many barriers that prevent primary care doctors from providing the complex care required by most youth with rheumatic disease: lack of time, lack of knowledge of these rare diseases and their treatment, and lack of specific knowledge about the impact of rheumatic disease on adolescent development. Well-developed adolescent medicine services are not universally available across North America or Europe. Therefore, the most common and practical model for transitional health care services for youth with rheumatic disease is a disease-focused transition from pediatric to adult rheumatology services.

When does transition begin and end?

When transition should begin and end remains controversial. Some transition programs suggest beginning early transition planning when the patient is 10 to 12 years old [29]. From a practical standpoint, many programs aim toward transition from pediatric health care services at the common social transition of high school completion, and frequently this transition may be dictated by administrative rules of the local health care system. One study from the United Kingdom examining transition programs for youth with type I diabetes in four districts in Oxford found that transition to adult health care services occurred between the ages of 13 to 22 years; the mean age of transition was 18 years [30].

The approach to transition currently adopted by a number of groups in North America, including the authors' program in Vancouver, begins to integrate some transition discussions with parents and children in mid-adolescence. Adolescents aged 15 years and older are generally seen alone by the physician and nurse for at least part of the clinic visit. Their parents join the patient for the portion of the visit that encompasses decision-making. Issues of independence in taking medications, communicating with the medical care team, school and vocation concerns, and lifestyle are addressed as part of the usual care for adolescents in the pediatric rheumatology clinic. At age 18 years, the rheumatology care of adolescents is transferred to a collaborative young adult transition clinic. A final transfer of rheumatology care to adult rheumatologist is individualized, depending on achievement of transition goals.

What goals should be adopted for a pediatric rheumatology transition program?

Transition clinics or programs can be an effective strategy to deliver targeted health care together and to prepare youth and young adults with childhood-onset rheumatic diseases for transfer to adult health care. This model of care provision is supported by the Canadian Pediatric Society Adolescent Medicine Committee [31].

The identification of clear goals for a pediatric rheumatology transition program can help assure that all participants recognize the scope of their responsibilities. Sharing the goals for the transition program with parents and youth helps define their expectations and their own responsibilities during this process. [Box 3](#) shows the set of goals used in the authors' transition program, the Young Adults with Rheumatic Diseases (YARD) Clinic. The goals were developed to reflect the developmental tasks of adolescents as well as to promote successful transfer to adult rheumatology care.

The Vancouver model for providing transition care to youth with rheumatic diseases: the Young Adults with Rheumatic Disease Clinic

The YARD Clinic was developed in Vancouver, BC, to address the need for providing developmentally appropriate rheumatology specialty care to youth over age 18 years with childhood-onset rheumatic diseases and to facilitate successful transfer of rheumatology care to the adult clinic. Many youth with rheumatic diseases are not prepared at age 18 years to have their rheumatology care transferred to the adult clinic, because they are still working through major

Box 3. Goals of a pediatric rheumatology transition program

1. Education
 - Knowledge about disease, medications, and roles of health care providers
 - Skills in communication with health care providers
2. Assist with separation from parents with respect to medical issues
3. Encourage adherence to medical recommendations
4. Provide assistance/guidance with issues of education, jobs/career, finances/health care coverage, independent living, and relationships outside the family
5. Implement final transfer to adult health care providers (rheumatologist and others as necessary), providing adequate records to new care providers

developmental issues. Therefore, the YARD Clinic provides a supportive environment and education in advocacy and independence skills aimed at eventual transfer to adult care at age 22 to 24 years.

The model for this clinic is shared clinical care by pediatric and adult rheumatologists in the same clinic setting, with a clinical nurse specialist, a social worker, established links with physiotherapy, occupational therapy, vocational and sexual counseling services, and a developing network of youth-friendly adult medicine subspecialists. The YARD Clinic has been functioning in its current format since 1995. The clinic is an integral part of the pediatric rheumatology program but is located at a different site.

The YARD Clinic functions with a set of principles that have been developed by the staff and modified as found necessary. The YARD clinic was developed to accept patients who have a definite diagnosis of a childhood-onset rheumatic disease and who have been followed in the pediatric rheumatology program at the British Columbia Children's Hospital. Patients are not accepted for new diagnostic evaluations, and patients over 17 years of age who are newly diagnosed with a rheumatic disease are generally not accepted. This decision was based on two considerations: (1) the limitations the available resources placed on the clinic's capacity, and (2) the belief that young adults aged 17 to 19 years who have lived with a childhood rheumatic disease have issues that are fundamentally different from those of patients with a new diagnosis at this age.

The move to the YARD Clinic is one important step in a process that begins in the pediatric rheumatology clinic several years earlier. At approximately age 14 or 15 years, the adolescent patients begin to spend a small amount of time alone with the pediatric rheumatologist and nurse. This time gives the clinic staff an opportunity for confidential discussions with the patient regarding adolescent health issues including sexual health, risk-taking behaviors, family problems, and vocational issues. Families are informed of the YARD Clinic as the patient reaches the age of 16 years. Transfer to the clinic generally occurs when the patient is 18 years old; for many patients, this is the year of graduation from high school.

One of the most important and often difficult issues in promoting a youth's independence during transition is the role and involvement of parents in their teen's health care. Most parents of children with a chronic rheumatic disease have spent many years organizing physician appointments, ensuring that medications are taken on time and regularly, getting medication renewals, performing or promoting physiotherapy and occupational therapy, and dealing with school and other community care providers. Many adolescents reach the age of 18 years without being able to name accurately their disease or medications; although they may have been given this information many times in the clinic, they are happy to let their parents take care of matters and have little incentive to assume responsibility themselves. Taking on independent health care responsibility is a late priority among the other areas of developing independence in their lives.

To smooth the transition from the parent-focused pediatric rheumatology program into the patient-focused YARD program, parents are invited to attend a

portion of their teen's first visit to the YARD Clinic, if the teen agrees. In the authors' experience, most transitioning adolescents attend their first visits completely on their own. After the first visit, parents are not invited to the clinic visits. Parents are actively discouraged from taking a coordinating role in the teen's on-going health care (eg, making or changing appointments, requesting prescription refills, or taking a leading role in medication decision-making). Indeed, the physician will not discuss any aspects of their child's care or progress without express permission of the patient, and parents are encouraged to obtain the information directly from the patient. For some parents, this transition is difficult. A clinical nurse specialist and social worker work with the young adult and, if necessary, the parent to provide support for the patient and family.

When is the final transfer to adult rheumatology?

Patients are generally followed in the YARD program for 3 to 5 years. This time allows the patient to have the additional supports of the YARD program during the critical period when the patient is engaged in making educational and vocational decisions, establishing strong independent peer relationships, and, for many young adults, leaving home and establishing independent living. The timing of the patient's final transfer to an adult rheumatology physician is individualized. [Box 4](#) shows the general goals used to assess readiness for transfer. At each YARD Clinic appointment after the age of 20 years, the team discusses the patient's readiness to transfer to adult care to identify areas that need further development.

Not all patients will have a successful transition from the pediatric rheumatology clinic through the YARD Clinic to adult rheumatology care. In the authors' experience, if the patient has not reached the transitional goals by 23 years, continuing in the program is unlikely to be of any benefit, and care

Box 4. Determining patient's readiness to transfer care to an adult rheumatologist

1. Patient has relatively stable disease.
2. Patient has adequate understanding of the disease and its treatments.
3. Patient has demonstrated ability to make and attend appointments and take care of medication needs.
4. Patient has developed an independent adult relationship with the health care providers in the YARD clinic.
5. Patient has a family doctor in the community and demonstrates the ability to use the family doctor appropriately.

is transferred. There are patients who have developmental delays, and their adolescent development may last late into adulthood. For some families, an enmeshed psychologic relationship between a parent and adolescent prevents the adolescent from developing independent health care behaviors.

What role can the pediatrician or primary care provider play in transition?

Frequently, the role of the pediatrician or primary health care provider is not well developed in considering issues of transition for youth with rheumatic diseases. In the model of the medical home promoted by the American Academy of Pediatrics [32], pediatric health care for children and adolescents should be a collaboration between parents and health care providers to provide accessible, community-based, coordinated health care. For youth with rheumatic disease, health care should incorporate the primary health care providers (pediatrician or family doctor, community based therapists), the subspecialty team (pediatric rheumatologist, nurse, subspecialty therapist, social worker, psychologist, and others), parents, school, and patient.

The primary health care provider should play an important supportive role for the family and patient by promoting a future planning perspective from an early stage [33].

Visits to the family doctor or pediatrician can provide an important opportunity for the adolescent to practice speaking to the doctor alone. These opportunities promote independence and the development of advocacy skills in an environment that feels safe and comfortable for the adolescent and the parents.

If the patient is followed by a pediatrician for primary health care, the transition to a primary care doctor (internist or family doctor) should be discussed and encouraged. This transition should take into account the needs of the young adult: does the patient prefer a male or female doctor, a group practice or solo practice? The young adult's choice of primary health care provider should be an integral part of the transition plan, because acquiring the skills to use a primary doctor properly is part of transition teaching.

Summary

The goals of pediatric rheumatologists are to ensure the best possible medical, functional, and social outcomes for their patients. Transition from pediatric to adult rheumatology care is a critical component of comprehensive care for adolescents and young adults with rheumatic disease. In the past few years, there has been increasing interest in the transition phase of pediatric rheumatology care and acknowledgment that best-quality services are not available to all patients. Improving transition care for youth with childhood-onset rheumatic diseases requires collaboration between pediatric and adult rheumatologists and between rheumatologists and primary care providers. Providers of transition care must

recognize that young adults with rheumatic diseases present complex medical and psychologic needs.

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