Transitions in Rheumatic Disease: Pediatric to Adult Care

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INTRODUCTION: WHY IS TRANSITION FROM PEDIATRIC TO ADULT CARE IMPORTANT?

The successful transition of the young adult patient with chronic disease to adult care is an important milestone in pediatric medicine. The ability to transition care, which for many with serious chronic illnesses may not have been possible in previous eras, reflects improved survival because of advances in preventive care and management of acute and chronic illness. In fact, 90% of children with chronic health conditions survive into adulthood, and around 500,000 young adults with special health care needs become adults each year. Among the estimated 18 million adolescents and young adults in the United States 18 to 21 years of age, about one-quarter have chronic health problems, including rheumatic diseases. Unfortunately, the transition from pediatric-centered to adult-centered health care can be a vulnerable period for young adults with a broad spectrum of rheumatic disease.

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- Rheumatology
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- Health care outcomes

KEY POINTS
- Young adults with a broad spectrum of rheumatic disease are vulnerable to poor health and outcomes, highlighting the importance of optimizing the transition to adult care.
- Too often, young adults are ill-prepared for adult care and face substantial challenges, including insufficient education and guidance, interruptions in care, and poor health and vocational outcomes.
- The ideal transition to adult rheumatologic care begins in early adolescence when patients, families, and pediatric providers start to prepare young adults to integrate easily into care with a prepared and proactive adult health care team.
- Primary care and rheumatology providers need to develop, study, and implement interventions to improve transition and transfer processes and health care outcomes for young adults.
- Quality improvement approaches such as the Six Core Elements of Health Care Transition offer opportunities to improve transition care for teens and young adults.

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adults with rheumatic and other chronic diseases. Hazards include gaps in continuity of care, poor treatment adherence, delays in establishing adult care, differences between adult and pediatric health care systems, inconsistent availability of appropriately trained adult providers, self-management challenges, and unstable medical conditions. The 2014 Institute of Medicine report, “Investing in Health and Well Being of Young Adults,” highlights the transition from pediatric to adult health care as an important component of improving the health of young adults, particularly those who have chronic disease.2

Without needed support and input from adult and pediatric providers through the transition process, young adults often experience decreased quality of care, increased health care costs, and poor health.3 Young adults are more likely to use the emergency department and to have lower health status and higher mortality compared with older and younger cohorts.3–9 The situation is even worse for minority and impoverished adolescents and young adults, who report being less likely to receive transition counseling, which likely contributes to health disparities for these populations.7

### Childhood-Onset Rheumatic Diseases Become Adult Problems

Most childhood-onset rheumatic diseases persist into adulthood. For example, more than half of the patients with juvenile idiopathic arthritis (JIA) experience active disease in adulthood, requiring ongoing management of immunosuppressive medications.10–12 Young adults with JIA are at increased risk to drop out of medical care, and some adult rheumatologists express discomfort in the medical management of JIA.13–16 Childhood-onset lupus is always a lifelong disorder. It is associated with high acuity and frequent hospitalization, risks of disability even in childhood, and higher morbidity and mortality compared with adult-onset lupus.17–20 Transitioning young adults with lupus are at risk for significant gaps in care.20 North American parents of youth with inflammatory myopathies report low awareness of transition policy and lack of a transition plan or medical summary.21 In a retrospective, single-center study of 31 patients with a variety of chronic rheumatic diseases, 58% had active disease when transferring to adult providers, 30% were hospitalized for disease flare in the year before transfer, and 30% experienced an increase in disease activity in the posttransfer year.22

Many young adults with chronic disease are also less likely to achieve college education and maintain employment and will have lower income compared with those without chronic disease.25 Young adults with JIA tend to have higher rates of unemployment, with some studies showing lower and others showing comparable education attainment compared with the general population.24–27 Those with childhood-onset lupus similarly have less employment than their peers despite similar education.28 Young adults with rheumatic disorders report problems with absenteeism, job disruptions due to illness, and productivity loss.29 They also express concerns about employers’ attitudes toward young adults with chronic diseases.30

### WHAT ARE THE BARRIERS TO SUCCESSFUL TRANSITION?

Several national surveys demonstrate that most adolescents, young adults, and their parents are inadequately prepared for the transition to adult care.1–5 Although some of the barriers to successful transition to adult care are disease specific, most young adults experience similar challenges across the spectrum of chronic diseases. A recent systemic review examining 57 disease-specific chronic illness transition studies identified the following common thematic barriers to transition: health care access/insurance; patient, parent, and provider beliefs/expectations; relationships; and
young adult and provider knowledge, skills, and efficacy. In addition, the neurologic and psychosocial development of adolescents and young adults, and problems with treatment adherence, are challenges to the transition process.

**Insurance and Access to Care**

Before the 2010 Patient Protection and Affordable Health Care Act (ACA) in the United States, approximately 50% of young adults reported gaps (on average lasting 15 months) in insurance coverage. The ACA expanded parental coverage for young adults up to age 26 years, so that the issue of inadequate coverage is shifted to 26- to 34-year-olds who are now the least likely to have reliable health care insurance. Compared with older counterparts, young adults are more likely to “churn” or change insurance frequently, introducing potential for delays in care because of required changes in providers or health care systems. Other challenges young adults face include finding conveniently located, qualified adult providers who accept their insurance, affording out of pocket medical costs and high deductibles, lack of confidence navigating insurance systems, and increased utilization of emergency departments for routine health concerns.

**Beliefs and Expectations**

Young adults and their families often have negative beliefs and expectations about adult care, and unfortunately pediatric providers sometimes promote these beliefs. The differences between adult and pediatric care models can produce a significant “culture shock” if young adults are not appropriately prepared for transition. As outlined in **Fig. 1**, the approaches in pediatric and adult health care differ. For example, a young adult who is used to a pediatric provider offering a longer appointment time may not appreciate the necessarily shorter visit with an adult provider and may perceive that quality of care is lower, regardless of outcomes. The adult provider may emphasize autonomy, efficiency, and respect for the patient’s time. Adult providers may describe young adult patients as ill prepared, dependent on parents, and “needy,” whereas both young adults and pediatric providers may view adult providers as disinterested or distant. The discordant expectations surrounding adult and pediatric care, if not negotiated properly, can contribute to challenges in young adults’ integration into adult care.

**Fig. 1.** The approaches to care in pediatric and adult health care differ, and if appropriate education and expectation setting do not occur during the transition process, the resultant “culture shock” can introduce the young adult transitioning to adult care.
Relationships

Adolescents and young adults with chronic rheumatic disease have often developed strong attachments to pediatric providers and can understandably be reluctant to leave a familiar and comforting environment. Pediatric providers can also be reluctant to “let go,” which can frustrate the transition process. Thus, the transition to adult care can be viewed by patients, families, and providers as a negative event than as an accomplishment. When a young adult sees an adult provider for the first time, it can be challenging for the adult provider to quickly establish the rapport and trust that existed in the long-term relationship with the pediatric provider. When adult providers fail to take some time to get to know young adult patients, they miss opportunities to gain young adults’ trust and confidence.

Knowledge, Skills, and Efficacy

Adult providers report that young adults entering adult care often lack knowledge about their disease history, medications, and the transition process. These knowledge deficits are compounded when appropriate medical records are not shared between providers. Unfortunately, poor adherence to treatment regimens and visit schedules is common among young adults, especially those who lack self-management skills and health literacy. Adult rheumatology practices may have less access to ancillary support, such as social workers, who can support struggling young adults or devote time to tracking down patients who do not show for appointments. In addition, adult providers may lack training and confidence concerning caring for young adults and miss opportunities to assess and encourage young adults’ self-care abilities. Many adult providers in private practice have limited appointment time, and those in academic institutions may lack institutional support for longer appointments to help accomplish successful transition. Further, most do not have established protocols for integrating young adults into their practice. Adult providers who assume care of youth with chronic disease often do not receive a summary of the medical records or educational information about the special needs of young adults with pediatric-onset diseases. Sharing of electronic medical records and summaries may help with this barrier.

Neurodevelopment

It comes as no surprise to parents and pediatric care providers that the adolescent/young adult brain functions differently from that of a young child or an older adult. Adolescents and young adults are well known for their creativity, emotionality, impulsiveness, risk-taking behavior, and heightened sensitivity to acceptance and rejection. Longitudinal structural and functional brain magnetic resonance imaging studies provide neurodevelopmental insight for these behaviors. The brain undergoes tremendous change between the ages of 11 and 25 years, including the expansion and later pruning of gray matter, marked synaptic proliferation and remodeling in the prefrontal cortex, and enhanced sensitivity to dopamine. As a consequence, adult-oriented executive function, emotional regulation, and decision-making care are not at their full capacity until the age of late 20s. In addition, adolescents and young adults with chronic health conditions, and especially those with disability, are at enhanced risk for mental health disorders including anxiety and depression, which may further affect neurodevelopment and behaviors. These findings have particularly important implications for medical management of young adults in the areas of adherence to treatment plans and negotiation of risk-taking behaviors in the setting of potentially toxic and teratogenic medications.
Adherence to Treatment

Available evidence and clinical experience suggest that adolescents and young adults are at particular risk for nonadherence to treatment, particularly medications. Medication adherence is challenging to measure, and available strategies include patient self-report, provider assessment, pill counts, and refill tracking. Of note, health care providers are poor in estimating patients’ adherence. In certain instances, laboratory values can serve as surrogate markers of adherence, including hemoglobin A1C levels in diabetics, viral loads in those with human immunodeficiency virus, and medication levels in transplant recipients. Measurements of hydroxychloroquine, mycophenolate, and 6-mercaptopurine levels have been used to estimate adherence in lupus patients. Commonly cited reasons for nonadherence include forgetting to take or refill medication, difficulty in obtaining refills, medical regimen complexity, and out-of-pocket medication costs. Rigorously studied interventions to improve medication adherence in adolescents and young adults are lacking, and creative interventions such as text reminders and financial incentives have shown mixed and often disappointing results. Available evidence suggests that routine electronic feedback to providers about medication nonadherence (eg, reporting delinquent medication refills) may lead to improvements in adherence but has not been shown to improve clinical outcomes. Other forms of nonadherence including failure to comply with treatment visits, laboratory monitoring, exercise regimens, and behavioral recommendations are also important but less well studied. Overall, although adherence to treatment regimens is very important in adolescents and young adults, clearly effective interventions to improve adherence remain an unmet need.

ASSESSING YOUNG ADULTS’ TRANSITION READINESS AND NEEDS

Assessing Readiness to Transition in Adolescents and Young Adults

In current practice, young adults are often ill-prepared or transfer abruptly and are not capable of functioning independently in the adult health care system. Several generic and condition-specific tools have been developed and validated to assess adolescents’ and young adults’ preparedness to function in an adult model of care. Examples of disease neutral tools include the Transition Readiness Assessment Questionnaire (TRAQ), the TRxANSITION Scale, and the Am I ON TRAC for Adult Care questionnaire. A Got Transition tool is also available (www.gottransition.org); this program will be discussed in more detail in later section. Common to all transition readiness measures are questions aimed at assessing young adults’ experience and comfort in interacting independently with providers, obtaining and taking medications consistently, and negotiating insurance and health care systems. The Patient Activation Measure (PAM) correlates with transition readiness. The Readiness for Adult Care in Rheumatology (RACER) questionnaire is specific to this subspecialty. Administration and tabulation of scorable transition readiness assessments can be billed by providers as health care assessments. Although higher scores on transition readiness instruments have not clearly been linked to successful transition or other transition outcomes, their utility for the primary care or rheumatology provider is in using them regularly to facilitate ongoing transition dialogue, needs assessment, and planning with patients and their families.

What Do Young Adults with Rheumatic Disease Want?

When surveyed, adolescents and young adults with rheumatic disease indicate that they prioritize having adult health care providers who view them as a person and
not a diagnosis want confidentiality and independence in their care and medical information. They are interested in knowing about the adult provider’s training and how to access adult health care. Young adults often prefer to adopt newer health care technology and communication platforms, such as electronic portals or texting, and may be unresponsive to information shared by telephone or mail.

MODELS FOR TRANSITION TO ADULT CARE

Generally, structured transition programs emphasize adolescent and young adult education, self-efficacy, decision-making, and self-advocacy. As shown in Fig. 2, the transition to adult care is a gradual process and as the adolescent matures, communication and decision-making are increasingly directed toward the patient than focused primarily on the parent. Optimally, the transfer of care occurs at a time when disease is well controlled, and for patients who have multiple health care providers, it is best if transitions to adult providers occur in a staggered fashion. Overall, the strategy is to support adolescent and young adults’ competence, confidence, and independence in self-management and coping. The transfer of care to an adult provider is the endpoint of the transition and, ideally, the young adult is seamlessly integrated into an adult practice.

There is a broad menu of approaches to managing transition, which includes disease-specific clinics, young adult clinics, collaboration with dual adult and pediatric trained providers, and use of transition coordinators to bridge adult and pediatric clinics. Most of the programs described in the literature are small, resource-intensive, highly dependent on specific local resources or grant funding, and likely not scalable to larger populations. Recent systematic reviews show that structured transition interventions in rheumatic and other diseases have achieved statistically significant positive results, but the overall quality of studies is low because of small size, opportunities for bias, nonrandomization, inadequate descriptions of interventions, variability in definitions of successful transition, and inconsistent outcome measurement. Very few transition studies have a “triple aim” approach, which requires evaluation of patient experience, population health, and health care cost. In a technical brief, the US Agency for Healthcare Research and Quality has recognized that the limited evidence base hinders determination of optimal transition interventions.

Fig. 2. The transition from pediatric to adult care is a gradual process, ideally beginning at age 12 to 14 years, during which the adolescent learns self-management skills and becomes more independent. As a result, self-care responsibilities and decision-making shift from parent to young adult. Transfer of care to an adult provider occurs at the end of the transition process.
HOW ARE WE DOING IN RHEUMATOLOGY?
State of Current Transition Processes for Adolescents and Young Adults with Rheumatic Disease

Pediatric and adult rheumatology providers have expressed dissatisfaction with the current state of transition processes for childhood-onset rheumatic disease. A survey of members of Childhood Arthritis and Rheumatology Research Alliance (CARRA), an organization that represents more than 90% of North American pediatric rheumatology providers, showed that 56% of respondents found current transition practices unsatisfactory; 90% lacked familiarity with the American Academy of Pediatrics (AAP), American College of Physicians (ACP), and American Academy of Family Physicians (AAFP) transition recommendations (discussed in later section); and only 8% reported using a formal transition policy in their practice. The most commonly reported barriers to implementing transition processes included poor provider training, limited time, low reimbursement, and inadequate access to resources and personnel. Most respondents (>80%) agreed with a need for rheumatology-specific guidelines for transition. Recent surveys of European pediatric rheumatology providers identified similar results. A 2014 survey of adult rheumatology providers who were American College of Rheumatology members identified poor familiarity with transition guidelines and lack of formal processes to integrate young adults into adult practices. Many (48%) stated that the medical history information they received from pediatric providers was inadequate, and more than 80% expressed a need for tools and guidelines to help with transition of young adults.

Do Transition Interventions Work in Rheumatology?

Although limited data are available concerning evidence-based transition improvement processes for adolescents and young adults with rheumatic disease, successful transition interventions in rheumatology have been described. For example, in the United Kingdom, a multisite, controlled trial evaluating a structured transition support program for adolescent and young adult JIA showed improvements in knowledge about JIA, use of transition plans, attendance rates at rheumatology appointments, and willingness to undergo joint injections without sedation. In the United States, small, single-center structured transition program interventions have improved rates of successful transfer of care to adult providers in patients with rheumatic disease. Most available studies, however, indicate that youth with rheumatic disease usually transition successfully to adult providers at best about half of the time. For example, in a three-year follow up of 16- to 23-year-olds with rheumatic and other chronic diseases receiving nonstructured transitional care, only 48% successfully transferred to adult care. Even in the setting of a coordinated Canadian rheumatology transition program, 52% of young adults with JIA failed to see an adult rheumatologist or experienced more than 1-year gap in care. Similarly, in a UK structured transition program, 57% of young adults with rheumatic disease did not satisfy predefined criteria for successful transfer of care to adult providers. Thus, even with interventions and deliberate planning, transition outcomes are often disappointing, suggesting that current approaches and practices do not adequately address the vulnerabilities associated with adolescent and young adult neurodevelopmental and psychosocial development and health care navigation.

Transition intervention studies in rheumatology and other chronic diseases tend to focus on satisfaction, quality of life outcomes, or rates of transfer to adult care. A critically important gap in current knowledge is whether transition process interventions...
can improve actual disease outcomes such as joint health in JIA, renal survival in systemic lupus erythematosus, or overall mortality. Outcome improvements after transition interventions have been demonstrated in small studies of renal graft survival in the setting of renal transplantation and in hemoglobin A1C levels in diabetes.77–79

ROLE OF PRIMARY CARE PROVIDERS IN TRANSITION TO ADULT CARE

Adult and pediatric primary care providers play vital roles in ensuring the successful transition to adult care.73 Limited available data suggest that, as in rheumatology practices, structured transition processes are often absent in primary care practices.80 Transfer from US pediatric to adult primary care tends to occur later than recommended and is susceptible to the same gaps in care characteristic of subspecialty transition care.81 Pediatric rheumatologists often see their patients more frequently than primary care providers do and may assume preventive care responsibilities, such as overseeing immunizations, performing sports physicals, and counseling on contraception. Although providing these preventive services in the subspecialty clinic can be convenient to families, it can also discourage the connection to the primary care provider and set up unrealistic expectations that adult subspecialists will function as primary care providers. In some studies, adult primary care providers express lack of interest or confidence in accepting young adults with chronic health conditions.81–83 Primary care transition models for complicated patients can include complex care clinics, young adult transition clinics, and dual internal medicine and pediatrics trained primary care providers. The need to develop appropriate self-management skills remains even when a young adult stays with the same provider during transition.

Transitioning adolescents and young adults with rheumatic diseases also need guidance concerning realistic and educational and vocational expectations, given their higher likelihood of unemployment and job maintenance and performance issues. In US public high schools, resources such as 504 plans and individualized educational plans are often needed. Providers can encourage linkage with disability services in the university setting. Referral to vocational rehabilitation can help young adults find appropriate employment, and adult providers can provide letters supporting needed accommodations to employers.

GUIDELINES AND SYSTEMS-BASED APPROACHES TO TRANSITION IMPROVEMENT

A 2012 joint clinical report from the AAP, ACP, and AAFP provides guidance to primary and specialty care providers concerning how best to support adolescents and young adults through the transition process, with specific age-specific recommendations (Fig. 3).84 These guidelines suggest that the process of transition planning begins at age 12 to 14 years, with a gradual preparation for adult care over the ensuing years, and that the actual transfer to adult care providers occurs between the ages of 18 and 22 years. More recently, the European League against Rheumatism (EULAR) and Pediatric Rheumatology European Society (PRES) provided rheumatology-specific guidelines for the transfer from pediatric to adult care, which are summarized in Box 1.85

Building upon the 2012 AAP, AAFP, and ACP clinical report, and to address the unmet needs of adolescents and young adults, Got Transition: The Center for Health Care Transition Improvement was founded. It is a US national center for health care transition funded by the Maternal and Child Health Bureau and The National Alliance to Advance Alliance Health, which has developed a systematic, quality improvement–
The 2011 joint recommendations from the American Academy of Pediatrics, American College of Physicians, and American Association of Family Practitioners provide age-based guidelines for the transition process. These recommendations apply to primary care providers and to specialists. (Data from American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics 2011;128(1):182–200.)

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**Box 1**

**Summary of European League against Rheumatism/Pediatric Rheumatology European Society recommendations and standards for transitioning young adults with rheumatic disease**

- Young adults need access to high-quality, transitional care
- Transition preparation must start as early as possible in adolescence
- Direct communication is needed between stakeholders (adolescent, young adult, parent, adult, and pediatric rheumatology providers) during the transition process
- Transition processes and progress should be planned with family and documented in medical record
- Adult and pediatric care services need to have a written transition policy
- There should be a written description of the transition multidisciplinary care team, and this team should include a transition coordinator
- Transition processes must be adolescent/young adult focused and developmentally appropriate
- A transfer document must be prepared
- Health care teams involved in transition must have appropriate training in adolescent care and childhood-onset rheumatic diseases
- There must be secure funding for resources to provide transition services to young adults with rheumatic disease
- There must be a freely accessible electronic-based platform to host recommendations and standards for transitional care
- Increased evidence-based knowledge is needed to improve outcomes for young adults with rheumatic disease

oriented approach to the transition process called the Six Core Elements of Health Care Transition. The Six Core Elements (shown in Fig. 4) provide practical and flexible recommendations for adult and pediatric primary and specialty care providers to implement in clinical practice. Adult and pediatric primary care and rheumatology providers can elect to implement all or select core elements, depending on available resources and population needs. Flexibility and creativity are encouraged in determining optimal ways to operationalize the six core elements in different institutions and clinical settings.

For pediatric providers, the Six Core Elements involve providing a transition policy, tracking and monitoring individuals going through the transition process, regularly assessing transition readiness, transition planning to encourage self-management skills, organized transfer of care to adult providers, and documentation of transfer completion. For adult providers, the Six Core Elements focus on having a policy for integrating young adults into practice, tracking and monitoring young adults’ self-management progress, and providing ongoing care. Got Transition’s comprehensive website (www.gottransition.org) offers several downloadable sample tools that can be customized for use in a variety of clinical settings. In addition, information concerning appropriate billing for transition-related clinical care is provided on the website. In concert with a multidisciplinary ACP effort, the American College of Rheumatology (ACR) developed transition resources to assist adult and pediatric providers in implementing the Six Core Elements (https://www.rheumatology.org/Practice-Quality/Pediatric-to-Adult-Rheumatology-Care-Transition). These ACR resources include a customizable draft transition policy and adult practice welcome letter, JIA and lupus medical summary templates, and condition fact sheets for adult providers. Additional websites that provide educational support to patients and families about transition include the following: The Arthritis Foundation (http://www.kidsgetarthritis.org/resources/transition-toolkit.php), the Lupus Foundation of America (http://www.lupus.org/resources/15-questions-transitioning-from-pediatric-to-adult-care), and the University of Florida transition program (https://hscj.ufl.edu/jaxhats/toolkit/).

A pilot project incorporating the Six Core Elements of health transition into a US Medicaid managed health care plan demonstrated feasibility. A health care transition learning collaborative of primary and subspecialty care practices in Washington, DC, Boston, Denver, Wisconsin, and New Hampshire implemented the six core elements using quality improvement methodology. The tools were

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**Six Core Elements Approach to Health Care Transition**

1. Transition Policy
2. Transition Tracking and Monitoring
3. Transition Readiness Assessment
4. Transition Planning
5. Integration into Adult Care
6. Transition Completion/Ongoing Care

**Fig. 4.** The Six Core Elements Approach to Health Care Transition includes development of transition policy, tracking and monitoring of transition progress, assessment of transition readiness, transition planning, integration of the young adult into an adult care model, and monitoring transition completion and ongoing adult care.
feasible to implement, and measurable improvements in transition and transfer processes were observed. The Six Core Elements have been adopted at a large pediatric medical center in collaboration with adult care colleagues, resulting in the availability of tools in the electronic medical record to assess and track transition readiness and progress and creation and sharing of medical summaries.

PUTTING IT ALL TOGETHER

In order to provide a practical example of how the Six Core Elements can be implemented into an academic subspecialty clinic or general pediatric practice, the following scenario is offered: the practice or division has several providers that may include physicians and nurse practitioners. A social worker serves as the transition coordinator. The practice develops a transition quality improvement team including administrative staff, a nurse, some of the pediatric care providers, an adult care provider from each of the few practices to which patients are most often referred, and the social worker who oversees transition projects. In an academic division, this team would also include a fellow. With parent and family input, a transition policy is developed (using ACR and Got Transition templates; see sample Fig. S1), which requires notification of patients and families that starting at age 14 years, providers will focus on fostering teen self-management skills. Families are also prepared that sometime between ages 18 and 22 years, the transfer to adult care will occur.

An information transition packet and annual self-management and transition readiness assessment visits with a nurse practitioner or other team member are offered to adolescents and young adults 14 years of age and older. At these self-management visits, transition readiness is assessed with a tool such as the Transition Readiness Assessment Questionnaire in order to identify strengths and opportunities for improvement and to develop specific plans to improve transition readiness. For example, the adolescent or young adult may set a goal to start requesting prescription refills or schedule future clinic appointments independently. At clinic visits, adolescents and young adults see care providers without a parent for at least a portion of the visit. At age 18 years, young adults are asked if they wish to provide consent for medical information to be shared with parent or guardian. Guardianship needs are addressed for young adults who have cognitive impairments.

If there is an electronic medical record, the practice or division develops tools to allow easy tracking of transition activities in the electronic medical record. Young adults who are expected to transfer to adult care within 12 months enter a transition registry, which initiates a structured process of identifying and scheduling an appointment with an adult provider, creating a medical summary and transfer letter (using the ACR and Got Transition templates; see sample Fig. S2), providing a transfer packet to the patient and adult provider and tracking to assure attendance at the initial appointment with the adult care provider is kept.

Adult providers are surveyed annually concerning the quality of medical records received and knowledge deficits observed in transitioning young adults. For subspecialty patients who take infusions, a transfer infusion roadmap is developed in collaboration with adult subspecialty colleagues and is provided to the adult care provider and the patient. The team also develops processes for young adults with cognitive impairment who may require guardianship, specifically trained adult providers, and other support, using resources available at the Got Transition website. Smaller primary
care practices and subspecialty centers could adopt similar approaches to implementing the six core elements, scaling the interventions according to available resources.

Programs such as the one described earlier have the best chance of success if the following conditions are in place:

1. Everybody in the practice supports the transition effort, including those who are not members of the transition team.
2. A member of the team has direct responsibility for insuring that the transition project operates as desired (in the example, it is the social worker).
3. Meetings to assess progress with the transition project are held regularly.
4. Quality improvement is practiced by making small changes in policy or procedure and assessing their success.
5. Parents and patients are given the opportunity for feedback on the transition program.

SUMMARY

It is not easy becoming an adult, especially for young adults with chronic rheumatic diseases who are at risk for continued active disease, morbidity, mortality, interruptions in care, mental health challenges, and suboptimal vocational outcomes. Starting early in adolescence, encouragement, education, and multidisciplinary support are needed from providers so that young adults can become confident in successfully navigating increasingly complex health care systems. Effective, feasible, evidence-based transition interventions that consider cost, satisfaction, disease outcomes, treatment adherence, and complex young adult neurodevelopment are needed to establish best practice transition processes. Fortunately, a growing interest in transition research, quality improvement, and advocacy promises a brighter future. Adoption of concepts such as the Six Core Elements of Health Care Transition may provide opportunities to promote creative, flexible, effective interventions that promote health resilience and improve outcomes for young adults grappling with rheumatologic disease.

SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at https://doi.org/10.1016/j.pcl.2018.04.007.

REFERENCES


