

Transition and transfer of the patient with paediatric-onset lupus: a practical approach for paediatric and adult rheumatology practices

Rebecca E Sadun,^{1,2} Laura E Schanberg^{1,3}

To cite: Sadun RE, Schanberg LE. Transition and transfer of the patient with paediatric-onset lupus: a practical approach for paediatric and adult rheumatology practices. *Lupus Science & Medicine* 2018;**5**:e000282. doi:10.1136/lupus-2018-000282

Received 15 June 2018
 Accepted 21 June 2018



© Author(s) (or their employer(s)) 2018. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Department of Pediatrics, Division of Rheumatology, Duke Health, Durham, North Carolina, USA

²Department of Medicine, Division of Rheumatology, Duke Health, Durham, North Carolina, USA

³Duke Clinical Research Institute, Durham, North Carolina, USA

Correspondence to

Dr Rebecca E Sadun; rebecca.sadun@duke.edu

ABSTRACT

The prevalence of paediatric-onset SLE (pSLE) is estimated at 1 million people worldwide and accounts for a significant proportion of SLE morbidity, mortality and cost. Patients with pSLE are especially vulnerable during and immediately following transfer from paediatric to adult rheumatology care, when substantial delays in care and increased disease activity are common. Transition is the process through which adolescents and young adults (AYA) develop the skills needed to succeed in the adult healthcare environment, a process that typically takes several years and may span a patient's time in paediatric and adult clinics. Recommendations for improving transition and transfer for AYA with pSLE include setting expectations of the AYA patient and family concerning transition and transfer, developing AYA's self-management skills, preparing an individualised transition plan that identifies a date for transfer, transferring at a time of medical and social stability, coordinating communication between the paediatric and adult rheumatologists (inclusive of both a medical summary and key social factors), and identifying a transition coordinator as a point person for care transfer and to monitor the AYA's arrival and retention in adult rheumatology care. Of paramount importance is empowering the adult rheumatologist with skills that enhance rapport with AYA patients, engage AYA patients and families in adult care models, promote adherence and encourage ongoing development of self-management skills.

CASE

An African-American woman was diagnosed with paediatric-onset SLE (pSLE) at age 16. Due to class IV lupus nephritis, she was initially treated with the United States' National Institutes of Health (NIH) protocol for cyclophosphamide, after which she was transitioned to mycophenolate for maintenance therapy. She did well for 3 years but lost Medicaid coverage at age 19 and subsequently stopped going to paediatric rheumatology clinic visits. Her primary care physician continued to refill mycophenolate, which she obtained via a patient assistance programme.

At age 21, she developed a mild flare and was admitted to adult medicine, where adult rheumatology was consulted and arranged postdischarge follow-up in the adult rheumatology clinic. When she arrived late to her second appointment, she was advised to reschedule and was not seen. She resurfaced 24 months later, having run out of medication and experiencing a severe flare with active lupus nephritis. She explained, "I kept waiting for the adult clinic to call me to reschedule, but they never did".

INTRODUCTION

pSLE is variably defined as SLE onset by or before age 18, or more strictly as onset by or before age 16.¹ pSLE is estimated to account for approximately 20% of all SLE cases,²⁻⁴ with most patients with pSLE cared for initially by paediatric rheumatologists. Five-year survival of pSLE now exceeds 95%,⁵ resulting in a growing number of youth surviving into adulthood and facing the challenge of transferring lupus care to adult rheumatologists.

The challenges facing chronically ill adolescents and young adults (AYA) as they transfer from paediatric to adult care are well documented for many disease processes. Morbidity, mortality and disease activity worsen immediately post-transfer.⁶ Several paediatric rheumatology studies have estimated that roughly half of patients are lost to care at the time of transfer,⁷⁻¹⁰ with a substantial percentage (10%–50%) dropping out between the first and second visit.¹⁰⁻¹² In addition, adult rheumatologists frequently do not feel equipped to assume care of patients with paediatric-onset disease,¹³ and AYA patients with chronic conditions often feel ill-prepared to transfer to adult care.¹⁴ pSLE is widely recognised as one of the most complex, severe and costly rheumatic diseases,¹⁵ making it simultaneously critical to transition effectively and

challenging to transition successfully. Regrettably, there is little published literature on transition needs and outcomes specific to the pSLE population,^{16–20} with most rheumatology transition literature looking either at all-comers^{7 10–13 21–31} or patients with juvenile idiopathic arthritis in particular.^{8 25 32–41} Nevertheless, it could be argued that patients with pSLE are among the most likely to struggle with transfer—and among the most likely to suffer significant morbidity, or even mortality, if they fall out of care.

Son and colleagues²⁰ examined the transfer experience of 50 patients with pSLE aged 18–23years old as they transferred to adult rheumatology care at their institution. The median transfer interval between the last appointment in paediatric rheumatology and the first appointment in adult rheumatology was 133days, while the mean transfer interval was 253days. It was not rare for the AYA to be out of care for several years after leaving paediatric rheumatology care, representing a potentially dangerous delay in care.

As with other specialties caring for medically complex and fragile AYA, rheumatology is looking to develop

processes to better prepare patients with pSLE for a successful transfer into adult care. ‘Transitional care’ is a term used to describe practices aimed at preparing AYA for the adult healthcare model and providing structure and support for patients’ ‘transfer’ from paediatric to adult care. Over the past decade, rheumatology has taken positive steps towards improving transitional care, and we herein review studies defining key challenges, discuss recommendations for the care of AYA with rheumatic diseases in general and pSLE in particular, and describe best practices and interventions with the potential to improve transition outcomes for AYA with pSLE. We also illustrate how the timing of transfer is crucial and underscore the need for bidirectional communication between the paediatric and adult rheumatology teams. In addition, we address differences between paediatric and adult care models (table 1) and emphasise the importance of transitional care as a process, beginning years before transfer and continuing years after transfer. We also offer two new tools (boxes 1 and 2) to aid rheumatologists—both paediatric and adult—striving to optimise AYA health during the transfer. Finally, we provide strategies (table 2) to help

Table 1 Common differences between paediatric and adult clinic settings

	Paediatric healthcare	Adult healthcare
Care orientation	▶ Family-centred (triadic).	▶ Patient-centred (dyadic).
Team approach	▶ Multidisciplinary.	▶ Reliant on referrals to other services.
Social work involvement	▶ Social worker often onsite.	▶ Social worker less available.
Appointment length	▶ Follow-up typically 30 min.	▶ Follow-up often 20 min or less.
Insurance	▶ Parental private insurance (until age 26 in the US). ▶ Medicaid (US governmental insurance assistance) available as a safety net until age 19.	▶ Not eligible for parental insurance past a certain age (27 in the US). ▶ Medicaid available only after burden of proof met demonstrating disability.
Educational/vocational needs	▶ Addressed and actively supported during clinic visits.	▶ Less commonly addressed or actively supported in clinic.
Late/no-show policy	▶ Patients typically accommodated despite tardiness or missed appointments.	▶ Patients often not seen if late; patients may be released from clinic for repeated missed appointments.
Trainee supervision	▶ Patients staffed in real time.	▶ Less direct supervision.
Medical care of SLE	▶ Vaccines often provided during specialty clinic visit. ▶ Patients’ primary care needs often addressed during specialty clinic visit. ▶ Aggressive steroid and cyclophosphamide dosing. ▶ Annual screening echo and PFTs common. ▶ Emphasis on minimising radiation during imaging studies.	▶ Unlikely to provide vaccines during specialty clinic visit. ▶ Patients usually required to see PCP for comorbidities and health maintenance. ▶ Less intravenous steroid pulsing; often lower doses of cyclophosphamide. ▶ Rarely screened with echo or PFTs unless indicated by history or suggestive symptoms. ▶ More likely to use CT.
Medication non-adherence	▶ Teams often ‘work around’ non-adherence by using intravenous medications.	▶ Physicians likely to hold patient accountable for non-adherence.
Follow-up interval	▶ Typically every 2–3 months.	▶ Typically every 3–6 months.

Adapted from Eleftheriou *et al*²² and from Tattersall and McDonagh.²⁹
PCP, primary care physician.

providers avoid or address common obstacles to smooth transfer.

VULNERABILITY OF AYA PATIENTS WITH PSLE

Patients with pSLE are more likely than their adult counterparts to develop lupus nephritis and neuropsychiatric manifestations.^{2 42–47} Due to severe disease, patients with pSLE are treated aggressively, often incurring more

drug-related toxicity than patients with adult-onset lupus.⁴⁶ Increased disease activity and medication-related morbidity result in significant SLE-related damage during childhood,^{48–50} as well as a twofold to threefold increase in SLE-related mortality compared with adult-onset SLE.^{43 51}

The increased severity of pSLE is compounded by decreased medication adherence in AYA.⁵² Poor adherence in pSLE is further complicated by the neurocognitive

Table 2 Strategies for improving transition and transfer outcomes

Problem/Obstacle	Paediatrics clinic strategies	Adult clinic strategies
AYA does not schedule with adult provider or misses the first adult rheumatology appointment.	<ul style="list-style-type: none"> ▶ Frame transfer as ‘graduating to adult care’; express confidence in adult provider. 	<ul style="list-style-type: none"> ▶ Communicate with paediatric provider when transferred AYA misses the first appointment.
	▶ Transition coordinator/registry.	
AYA drops out of care after the first adult rheumatology clinic visit.	<ul style="list-style-type: none"> ▶ Prepare AYA for what to expect from adult clinic and provider, highlighting: <ul style="list-style-type: none"> – Process differences. – Differences in clinic culture. – Medical practice differences. ▶ Communicate with receiving adult provider before the first visit, using the TRANSFER mnemonic. 	<ul style="list-style-type: none"> ▶ Use the WELCOME mnemonic: <ul style="list-style-type: none"> – Use the first visit to develop rapport with AYA and parent(s). – Align with paediatrics provider the WELCOME mnemonic. – Minimise medical changes during the first visit. ▶ Communicate back to paediatric clinic after AYA’s first visit.
	▶ Transition coordinator/registry.	
AYA lost to follow-up due to poorly timed transfer.	<ul style="list-style-type: none"> ▶ Avoid transfer during medical flare, pregnancy, other major life events. ▶ Consider adult comanagement rather than full transfer of care. 	
AYA lost to follow-up due to scheduling policies.	<ul style="list-style-type: none"> ▶ Prepare AYA/family regarding scheduling expectations and rules of adult clinic. 	<ul style="list-style-type: none"> ▶ Delineate expectations to AYA/family. ▶ Encourage AYA to save office phone number in cell phone. ▶ Advise AYA not to cancel without rescheduling.
AYA struggle in adult clinic due to lack of self-management skills.	<ul style="list-style-type: none"> ▶ Use readiness assessments (eg, TRAQ or Got Transition) to guide transition preparation and help determine transfer time. 	<ul style="list-style-type: none"> ▶ Use readiness assessments (eg, TRAQ or Got Transition) to guide ongoing development of self-management skills.
Adolescent medicine aspects of health not explicitly addressed in the adult clinic.	<ul style="list-style-type: none"> ▶ Ask parent to leave room for all AYAs >16 years (or >12 years). ▶ Encourage AYA to ask and answer questions independently. ▶ Connect AYA with community resources prior to transfer. 	<ul style="list-style-type: none"> ▶ Establish expectation that AYA answers questions first. ▶ Perform social history with parent(s) out of the room; use HEADSS or other adolescent-focused approach to the history. ▶ Assess potential barriers to care (health literacy, transportation, adherence, contraception and others). ▶ Use available social work and community resources.
Poor medication adherence.	<ul style="list-style-type: none"> ▶ Consolidate medications (eg, number, dosing frequency). ▶ Provide pillbox or consider prescribing blister packs. ▶ Encourage free medication reminder apps like Mango Health. ▶ Help patient overcome financial barriers by using a drug company patient assistance programme, applying for other medication support (www.needymeds.org) and identifying the least expensive pharmacy (www.goodrx.com, www.lowestmed.com). 	

AYA, adolescents and young adults; HEADSS, Home, Education/employment, Activities, Drugs, Sex/Sexuality, Suicide/depressio; TRAQ, Transition Readiness Assessment Questionnaire.

and memory impacts of SLE,⁵³ as well as high rates of comorbid depression and anxiety.^{20 54} Furthermore, myelination and pruning of the prefrontal lobes continues through the early 20s, such that AYA patients are still developing abstract and long-term reasoning skills, including delayed gratification and consideration of distant consequences.^{55 56} In addition, children with chronic illness are often less mature than healthy peers due to the stagnation or slowing of social maturation that can occur at the time of a life-altering diagnosis^{57–59}; as such, a 21-year-old with pSLE onset at age 13 may have self-management skills more closely resembling a typical 13-year-old's skills than a typical 21-year-old's skills, and this can be perpetuated by parents who become overprotective when faced with their child's critical illness. Finally, risk-taking behaviours and rebellion are developmentally appropriate for AYA, and when superimposed on chronic illness often manifest as non-adherence, which in turn leads to poorly controlled disease.

Healthcare disparities further complicate the care of many AYA patients with pSLE.⁶⁰ Lupus disproportionately affects the socioeconomically disadvantaged^{61 62} and those exposed to trauma and repetitive stress⁶³; such social circumstances also interfere with patients' and families' ability to prioritise healthcare. SLE disproportionately affects ethnic or racial minorities who are already experiencing a multitude of healthcare disparities.^{62 64 65} In addition, Hispanic and African-American patients with SLE have higher rates of SLE disease activity, damage accrual, hospital readmission, admission to the intensive care unit and mortality.^{60 66} This can be further compounded by the fact that AYA patients from several ethnic minorities score lower than Caucasian AYA patients on transition readiness measures.¹⁴ It is therefore the ethnic minority AYA with pSLE coming from a low socioeconomic status who may be the most at risk.^{60 64 65}

Unfortunately, it is during the tumultuous period of adolescence—when AYA patients are often at their most vulnerable due to changes in school, jobs, relationships, insurance, independence and housing—that many healthcare systems require transfer from paediatric to adult care, where the medical culture is palpably different. One reason such a large percentage of transferring young adults fail to successfully establish themselves in an adult rheumatology setting is a lack of the social and emotional maturity needed to thrive in a healthcare system characterised by patient autonomy and responsibility.²⁹ For some AYA patients in the US, loss of Medicaid at age 19 may precipitate abrupt transfer to adult care earlier than desired by the patient or the paediatric provider; with roughly one-third of young adults with pSLE unemployed,^{17 19 67} patients' ability to consistently access the adult healthcare system may be significantly impaired by insurance insufficiencies.

However, laying the blame exclusively on socioeconomic challenges (unreliable transportation, distance from a tertiary care centre, difficulties affording medication and other healthcare disparities) ignores the fact

that many of the same limiting factors were present when the AYA patient successfully engaged in paediatric care. We must therefore try to understand what modifiable factors interfere with AYA making it to a first visit in an adult rheumatology clinic and what factors prevent those who have a first visit from returning.

In addition to examining structural burdens that contribute to the attrition of transferred patients with pSLE, it is important to acknowledge the emotional challenges that AYA and their families face when leaving a long-standing, safe relationship with a paediatric rheumatologist and 'starting over' with a new physician. In a survey that asked transferred patients with pSLE to reflect on their transfer experience, a quarter of patients reported 'difficult emotional adjustment due to loss of pediatric providers'.¹⁷ Patients and families benefit from practitioners—on both sides of the transfer—openly acknowledging the difficulty of leaving a trusted paediatric team and adjusting to a new adult team. Many patients and families are understandably fearful of the unknown; their early experience of adult care may be less jarring and objectionable when healthcare providers have explained, in advance, what to expect from the transfer process and what to anticipate regarding structural and cultural differences between paediatric and adult care (see [table 1](#)).

In the UK there has been a concerted effort to decouple transfer from the challenging timing of early adolescence by including an adolescent rheumatology specialist in the care continuum.^{22 68} Eleftheriou *et al*²² describe their practice of transferring patients ages 13–15 from a paediatric rheumatologist first to an adolescent rheumatologist. The adolescent rheumatology clinic focuses on the development of self-management skills before patients transfer to an adult rheumatology clinic at age 18 or older. Adolescent rheumatologists expect higher levels of patient autonomy and responsibility than providers in the paediatric setting, but not so much as is demanded in the typical adult clinic.

It is important to consider the UK model and other approaches designed to improve transition in rheumatology^{10 37 69–78} as well as several well-studied non-rheumatologic chronic conditions,^{79–84} in light of the bleak data on post-transfer outcomes of patients with pSLE, including increased disease activity,⁴² disease damage²⁰ and depression.^{20 54} Given the vast resources spent on medical care for children and adolescents with pSLE,¹⁵ incremental investment in modest transition services—such as the training of rheumatologists in transition best practices and the hiring of transition coordinators—is likely a cost-effective means to improve the percentage of successful transfers and thereby improve clinical outcomes for young adults with pSLE.

EXPERT OPINION GUIDELINES

A recently published European set of recommendations for pSLE included transition as a critical element of care,

specifying that ‘a coordinated transition programme including paediatric and adult specialists is crucial for ensuring continuity of care and adherence to treatments in order to optimize long-term outcomes including prevention of fatalities’.⁸⁵ The authors further advised that adolescent patients be supported through the transition and transfer process, advocating for concerted efforts to develop adolescents’ self-management skills and address the challenges of non-adherence. In addition, a 2011 review of pSLE management supported integrating ‘adherence to medications and clinic visits as well as self-management training’ into the routine care of patient with pSLE.⁸⁶

Looking at transition and transfer best practices for the broader category of paediatric rheumatology patients, a 2015 consensus statement from the Spanish Society of Pediatric Rheumatology used a Delphi process to establish 18 recommendations, including training paediatric rheumatologists and related healthcare professionals in translational care.⁸⁷ In addition, in 2016 the European League Against Rheumatism (EULAR) and the Paediatric Rheumatology European Society (PReS) jointly published transition recommendations for AYA with paediatric-onset rheumatic diseases⁷ based on the input of 200 European adult and paediatric rheumatology specialists. This report made 12 recommendations, including that every rheumatology service has a written transition policy and that providers begin discussing transition with patients in early adolescence. The EULAR/PReS guidelines also recommend that transitional care be individualised, based on the needs and abilities of patients and their families, addressing medical, psychosocial, educational and vocational needs. The recommendations also stipulate that a transfer document should accompany transferring patients, that there should be direct communication between the paediatric and adult rheumatologists both before and after transfer, in addition to the involvement a designated transition coordinator. Analyses of multiple published transition programmes point to the pivotal role of a transition coordinator as a main contributor to successful outcomes.⁷⁰

Tracking AYA outcomes post-transfer is a valuable role for the transition coordinator and helps guide the development, refinement and implementation of transition interventions. As Foster *et al* point out in the EULAR/PReS recommendations, one challenge in transition research is the lack of a single outcome of ‘successful transition’.^{7, 23} The literature is highly varied with regard to what constitutes key indicators of successful transition and transfer,^{7, 88, 89} with candidates including disease activity and status, patient (and family) experience of care, adherence to treatment, patient engagement in care, and achievement of young adult development tasks, including psychosocial, educational and vocational status outcomes.

PREPARING THE PATIENT: TRANSITION BEST PRACTICES FOR THE PAEDIATRIC RHEUMATOLOGIST

When and how to start

As per published guidelines, best practices include initiating conversations regarding transition and transfer at age 12,^{90, 91} introducing the clinic’s transfer policy as part of the conversation, and outlining patient, parent and healthcare provider expectations. It is important to note, however, that Chira *et al*²¹ showed that only 8% of responding US and Canadian paediatric rheumatologists have a formal written transition policy.

Explaining ‘transition’ and ‘transfer’ to families

Learning to drive a car is a commonly used, relatable analogy. ‘Transition’ is the period during which a teen takes driver’s education, reads the driver’s manual and gets hands-on practice behind the wheel. It is acknowledged that a person cannot safely drive on the freeway on his or her first hour behind the wheel; rather, this is a skill that a new driver works up to, after mastering easier skills, and with an adult driver sitting alongside to offer feedback and to assist if necessary. ‘Transfer’, however, is like being handed the keys to a car for unsupervised driving; one hopes this happens only after the AYA demonstrates acquisition of fundamental driving skills. Just as it would be dangerous for someone to drive independently without the training and practice that leads to a driver’s licence, it is dangerous for a young adult to leave for college or other independent living opportunities before he or she has practised self-management skills, such as medication management, in a safe environment. The ‘shared management model’ illustrates the goal of the parent gradually transitioning from ‘care provider’ to ‘manager’, then to ‘supervisor’, and finally to ‘consultant’ over the decade that the AYA patient transitions from ‘care receiver’ to ‘care participant’, then to ‘manager’, and ultimately to ‘supervisor/CEO’.⁹²

How to frame transfer

Most AYA and their parents are inherently apprehensive about leaving the familiar paediatric environment. Well-intentioned paediatric provider statements, such as ‘Don’t worry, we won’t kick you out until you’re 21’, while meant to be reassuring to young patients and their families, often perpetuate the sentiment that adult medicine is scary, undesirable or even dangerous. Instead, a statement like ‘We expect that you’ll be ready to graduate to adult care sometime between the ages of 18 and 21’ frames transfer in a more positive light and helps patients and parents think about transfer as a developmentally appropriate step. Transfer should be approached with the family as an opportunity for growth rather than being used as a punishment for poor adherence or held out as a threat meant to improve adolescent behavior, because families pick up on the underlying subtext and may lose trust in adult care.

Developing self-management skills

Self-management has been defined as an “individual’s ability to manage the symptoms, treatment, physical and

psychosocial consequences and lifestyle changes inherent in living with a chronic condition".⁹³ AYA must learn self-management skills, such as filling and taking medications, scheduling and keeping medical appointments and communicating with the healthcare team during and between visits in order to effectively manage their disease while living independently.⁹⁴ Many families assume it is appropriate for parents to continue performing many of these functions until the AYA leaves home, but self-management has been shown to increase self-efficacy, improve coping skills and positively impact health; graduated self-management is therefore desirable throughout adolescence.^{95,96} In addition, as with the driving example, skills take time to develop. Focusing on self-management early in adolescence enables AYA with pSLE to develop concrete, technical skills, in addition to developing more nebulous problem-solving skills,⁹⁶ which are also crucial to the management of disease flares and other unexpected health challenges. Finally, self-management skills lead to self-advocacy skills and increased self-confidence,⁹⁷ patient activation and a sense of partnership in one's own healthcare, all of which buffer an AYA patient from using non-adherence as a way of expressing age-appropriate rebellion.⁹⁶

Transition readiness assessments

Starting in early adolescence, self-management skills and transition readiness should be measured at least annually. Certain patient characteristics can predict likelihood of readiness at a cohort level,⁹⁸ but identification of an individual's readiness should be assessed using tools such as the Transition Readiness Assessment Questionnaire (TRAQ)^{99,100} or the Got Transition Readiness Assessment,¹⁰¹ both of which can be accessed online through the web page of the American College of Rheumatology (ACR).¹⁰² Clinics may find it helpful to provide the assessments to patients in the waiting room or through health system portals prior to the clinic visit. Glancing at a completed readiness assessment, a healthcare professional can rapidly determine whether a patient's self-management skills are excellent, poor or somewhere in the middle. This information can help guide how much of a clinic visit should be devoted to discussing self-management skills and on which particular skills the conversation should focus. As a patient nears the age of transfer, the tools should be used at every visit to set goals for the development of skills needed prior to transfer (eg, 'I see that you already call for your own refills, but that you don't yet call to make your appointments — is that something you would be willing to try doing on your own between now and your next appointment?'). The 2016 EULAR/PReS recommendations underscore the importance of documenting readiness assessments in the medical chart so that progress can be monitored at subsequent visits.⁷

Establishing a transfer date

For developmentally and cognitively normal AYA, a transfer date should be established in part based on

self-management skills. Best practice includes working with the family to establish a transfer date at least 12 months in the future, such that the family and health team can work towards the AYA being sufficiently prepared by that date. Patients with neurodevelopmental delays or major psychiatric comorbidities may take longer or may never reach a period of independent self-management, though a transfer date will eventually be set with the input of the patient and family. For such patients, it may be helpful to clearly establish goals and expectations regarding what the AYA will do independently by the transfer date and what roles the parent or guardian will continue to fulfill even after transfer. In addition to optimizing self-management skills prior to transfer, transfer ideally should take place during a time of [relative] medical and social stability. Transfer during a disease flare introduces discontinuity of care during a medically vulnerable time and often leads to bad outcomes. Similarly, transfer during a socially challenging time — such as pregnancy or soon after the birth of a child, or during a change of school, job, or insurance — introduces discontinuity of care when the AYA has less emotional reserve and is more likely to prioritize other aspects of life above his or her health.

TRANSFERRING THE PATIENT: BEST PRACTICES FOR PAEDIATRIC AND ADULT RHEUMATOLOGISTS

Preparing the patient for transfer

In addition to the transition work described above, the AYA and family should be oriented to what to expect in adult care. As outlined in [table 1](#), in the typical adult practice, visits may be shorter, there may not be a social worker available onsite, screening procedures (eg, echocardiograms or pulmonary function tests) may not occur by routine and medication dosing may differ. Additionally, late and no-show policies are often more stringent and strictly enforced. Other known practice-specific differences can be shared as well, minimizing the likelihood that a family interprets deviations from the pediatric norm as a sign that the adult provider is incompetent. It is helpful for the pediatric provider to reassure the family ahead of time about the appropriateness of different approaches to care.

Preparing the receiving provider

The EULAR/PReS recommendations emphasise the importance of both a medical summary and direct contact between paediatric and adult rheumatology providers, both before and after the first visit to the adult rheumatology clinic.⁷ The medical summary was ranked as one of the two most important aspects of successful transition by adult physicians,¹⁰³ but only 16% of paediatric rheumatologists in North America report routinely providing a medical summary.²¹ In addition to the medical summary, having a formal, written transition plan is considered a best practice,³⁷ and using the electronic health record system is thought to facilitate this task.¹⁰⁴

Box 1 TRANSFERS

Communication between paediatric and adult rheumatology providers before the first adult visit, as a supplement to a written medical summary.

- ▶ Treatment history.
- ▶ Recent complications, Recent medication changes and so on.
- ▶ Adherence challenges (including assessment of root causes).
- ▶ Needs (eg, referral to adult nephrology, establish with mental health provider).
- ▶ Social history and Social challenges.
- ▶ Financial/insurance challenges.
- ▶ Emotional or intellectual challenges.
- ▶ Reasons this a good (or precarious) time for transfer.
- ▶ Summary of patient characteristics (eg, favourite activities, academic interests, professional goals, personal values).

There are multiple templates regarding the content of a thorough medical summary, including tools available on the websites of the ACR¹⁰² and Got Transition.¹⁰⁵ However, little is published to guide providers on the content of their ‘handoff’ conversation, although this communication is a core recommendation.⁷ To provide structure for this conversation, we developed the TRANSFERS mnemonic (see [box 1](#)), which includes key topics for the paediatric and adult rheumatology providers to discuss shortly before the patient’s first adult appointment. Beyond relaying medical history, the pretransfer conversation between paediatric and adult rheumatology providers is an opportunity for the paediatric provider to share psychological, social and interpersonal factors that impact the patient’s care, including the AYA’s strengths and weaknesses and the family’s dynamics. For example, a paediatric provider might convey that the AYA and her mother may sound agreeable to starting a new medication during a clinic visit, but once home the grandmother usually convinces them to use herbal remedies instead.

Transfer

The appointment of a ‘transition coordinator’ has been identified as one of the most important elements of transition programmes.⁷⁰ The coordinator often has a nursing or social work background, but these degrees are not strictly necessary. The transition coordinator typically meets with the AYA and the family before transfer and remains available to them as a resource during and immediately following transfer. Often the coordinator will orient the AYA and the family to differences between paediatric and adult practices and help the AYA assess and develop self-management skills. In addition, the coordinator is often responsible for keeping a list or registry of transferring AYA and checking in with the AYA periodically. If the transition coordinator identifies a gap in care, the coordinator will reach out to the AYA, enquiring about obstacles in an effort to resolve them.¹⁰⁶ The role can be modelled on the transplant coordinator role used nearly universally in the US for transplant recipients.

Box 2 WELCOME

Steps for the adult rheumatology provider to take when a patient arrives from paediatric care.

- ▶ Welcome and congratulate the patient on graduating to adult care.
- ▶ Explain key similarities and differences (medical and structural) between paediatric and adult care.
- ▶ Let patient and parents know their respective roles (eg, the patient answers questions first, after which input from parent welcomed).
- ▶ Communication ongoing with the paediatric provider: reassure he patient you are in touch as needed.
- ▶ Opportunity for the patient and parents to ask questions about the new clinic (before beginning medical aspects of the visit).
- ▶ Minimise medical changes during first adult clinic visit.
- ▶ Expectations: supportively convey expectations of the patient and parents (eg, arrive 10 minutes prior to your appointment).

RECEIVING THE PATIENT: TRANSITION BEST PRACTICES FOR THE ADULT RHEUMATOLOGIST**The first visit**

Given that a large percentage of AYA patients who arrive to a first adult rheumatology visit do not return for a follow-up visit, the first visit should be viewed as a critical opportunity to win—or lose—the trust of the transferring AYA and the family. There are limited data regarding practices that optimise the retention of transferring patients, although Taylor⁹⁶ offers an informative review of rapport-building skills to facilitate working with AYA with rheumatic diseases. Earning the trust of the parent(s)^{107 108} is also important to retaining the patient in the AYA clinic and should be one focus of early visits. To aid the adult rheumatologist seeing an AYA patient for the first time, we used existing literature and personal experience to develop the WELCOME mnemonic (see [box 2](#)). The goal of these skills is for the AYA and the family to achieve a level of comfort and trust with the new provider, often by demonstrating alignment between the paediatric team and the new adult provider and by the adult provider demonstrating that he or she cares about the AYA as a person.¹⁰⁹ Therefore, it is advisable to minimise medical changes during the first visit, deferring non-critical changes until after rapport and trust have been established.

Ongoing transition work

Although a few young adults are able to master self-management prior to transfer, the vast majority are not. Therefore, transition readiness assessment tools continue to be helpful in the adult clinic. The tools from TRAQ, Got Transition and the ACR provide a time-efficient way to identify and target existing gaps in self-management skills, helping young adults set realistic goals for developing skills between clinic visits. Akre *et al*⁸¹ identified key tasks for the adult rheumatologist to engage in with AYA patients during the years following transfer. In addition, certain elements of the social history, such as reproductive health and contraception use, are part of the care of all adults with SLE¹¹⁰ but are especially important in the AYA population.

ADDRESSING MEDICATION ADHERENCE

Adherence should be addressed with all patients with SLE, whether they are being seen in paediatric or in adult clinics, given the very low medication adherence rates in this patient population. The Medication Adherence Self-report Inventory (MASRI), which can be completed by a patient during a clinic visit, has been shown in SLE to correlate moderately well with medication position data obtained from pharmacies¹¹¹; however, in a subset of patients with poor adherence, the MASRI dramatically overestimates adherence,¹¹¹ and this may be an even greater problem with AYA patients, who may not be forthcoming about non-adherence due to concerns regarding parental repercussions. Concerningly, using-pharmacy claims data in a large Medicaid population, recent estimates of adherence to steroids, hydroxychloroquine, azathioprine and mycophenolate of patients with SLE fell in the range of 15%–20%,^{112 113} with adherence being worst among young adults⁵² and those with depression.^{52 114–116}

Targeting the memory aspect of adherence, mobile apps such as Mango Health are thought to have significant potential for improving adherence in the AYA population.¹¹⁷ Pillboxes¹¹⁸ and blister packs¹¹⁹ may also help AYA patients with SLE remember their medications, although many patients with SLE report intentional non-adherence¹²⁰ for reasons that include ‘side effects’ and ‘too many pills’.¹¹⁸ Indeed, reducing the number of medications and simplifying dosing have been demonstrated to improve adherence in multiple disease states.¹²¹ However, for many patients with SLE, ‘difficulty in accepting [having] a chronic disease that requires life-long therapy’¹²² lies at the core of non-adherence. Excitingly, a recent pilot study showed promise in addressing this challenging cause of non-adherence by demonstrating increased hydroxychloroquine adherence rates in AYA patients with SLE who answered questions on a social media forum compared with those who answered the same questions in a journal.¹²³ Connecting AYA with peers can create a sense of community as well as a sense of agency, which can combat denial, helping AYA engage in constructive behaviours such as medication adherence.¹²⁴

SUMMARY

Revisiting the case of the African–American pSLE patient discussed at the beginning of this article, one can identify several missed opportunities to increase the likelihood of a successful transition and transfer to adult care. First, the patient's upcoming loss of Medicaid insurance could have been anticipated and she could have received pre-emptive counselling regarding options for maintaining seamless coverage (Medicaid extension, coverage through the Affordable Care Act, student insurance or employer insurance—including from a known subsets of companies that offer health insurance to part-time employees). In addition, rather than the abrupt transfer that occurred during an inpatient admission for a lupus flare, transfer could

have been planned for a time of medical stability, when a goal transfer date could have been set so that the patient, family, paediatric rheumatologist, adult rheumatologist and primary care physician were all working towards the same goal. Finally, the patient reported waiting for the adult clinic to reschedule, illustrating the chasm between the adult rheumatology clinic's expectations and her previous experiences in her paediatric rheumatology clinic. Perhaps she would not have been lost to care if she had been better prepared for the adult clinic's stricter late policy, if she had been warned that in the adult clinic rescheduling is the patient's responsibility, or if there had been a safety net such as a transition coordinator and a registry of transferred patients to alert the healthcare team to her extended absence.

Recognising how challenging and perilous the journey can be between the paediatric rheumatology clinic and the adult rheumatology clinic—even when they are located in the same health centre—it is clear that paediatric and adult rheumatology providers must work together to help AYA with SLE complete the journey. Much of the preparatory work falls on the paediatric clinics, where considerable time is invested in helping AYA develop self-management skills. Paediatric providers can ease the patient's transition by gradually increasing the self-management expectations as patients age and mature, while adult clinics add AYA-focused safety net measures and social support staff to ease the transition. Specific strategies to improve transition outcomes are highlighted in [table 2](#). Alongside published transition best practices,⁷ these strategies can be implemented in tertiary care institutions and free-standing private practice clinics alike in order to improve the transition and transfer of young adults with pediatric-onset lupus, optimizing their health before, during, and after transfer to adult care.

Ultimately, paediatric rheumatology and adult rheumatology must both assume ownership over transition and transfer, recognising this work as a vital element of caring for AYA with SLE. Developing joint transition goals with AYA and their families—and communicating them between paediatric and adult providers—allows for individualised transition plans that coordinate the efforts of the patient, the family and the medical team to ensure the ongoing health of young people with pSLE.

Contributors Both authors were involved in the design, writing and editing of the manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent Not required.

Provenance and peer review Commissioned; internally peer reviewed.

Data sharing statement No additional data are available.

Open access This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0>

REFERENCES

- Ardoin SP, Schanberg LE. Paediatric rheumatic disease: lessons from SLE: children are not little adults. *Nat Rev Rheumatol* 2012;8:444–5.
- Kamphuis S, Silverman ED. Prevalence and burden of pediatric-onset systemic lupus erythematosus. *Nat Rev Rheumatol* 2010;6:538–46.
- Klein-Gitelman M, Reiff A, Silverman ED. Systemic lupus erythematosus in childhood. *Rheum Dis Clin North Am* 2002;28:561–77.
- Malattia C, Martini A. Paediatric-onset systemic lupus erythematosus. *Best Pract Res Clin Rheumatol* 2013;27:351–62.
- Tektonidou MG, Lewandowski LB, Hu J, et al. Survival in adults and children with systemic lupus erythematosus: a systematic review and Bayesian meta-analysis of studies from 1950 to 2016. *Ann Rheum Dis* 2017;76:2009–16.
- Betz CL. Approaches to transition in other chronic illnesses and conditions. *Pediatr Clin North Am* 2010;57:983–96.
- Foster HE, Minden K, Clemente D, et al. EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Ann Rheum Dis* 2017;76:639–46.
- Hazel E, Zhang X, Duffy CM, et al. High rates of unsuccessful transfer to adult care among young adults with juvenile idiopathic arthritis. *Pediatr Rheumatol Online J* 2010;8:2.
- Hersh A, von Scheven E, Yelin E. Adult outcomes of childhood-onset rheumatic diseases. *Nat Rev Rheumatol* 2011;7:290–5.
- Jensen PT, Karnes J, Jones K, et al. Quantitative evaluation of a pediatric rheumatology transition program. *Pediatr Rheumatol Online J* 2015;13:17.
- Chanchlani N, Harewood C, Hossain U, et al. Better transition readiness for adolescents begins with effective communication. *J Pediatr Hematol Oncol* 2015;37:574–5.
- Chanchlani N, McGee M, McDonagh JE. Informational continuity is integral for successful transition of adolescents to adult care. *J Rheumatol* 2015;42:901–2.
- Zisman D WP, Chira P, Ardoin SP. Adult rheumatologists perspective on the transition process for young adults with rheumatic conditions [abstract]. *Arthritis Rheumatology* 2015;67.
- McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics* 2013;131:1090–7.
- Brunner HI, Sherrard TM, Klein-Gitelman MS. Cost of treatment of childhood-onset systemic lupus erythematosus. *Arthritis Rheum* 2006;55:184–8.
- Falcini F, Nacci F. Systemic lupus erythematosus in the young: the importance of a transition clinic. *Lupus* 2007;16:613–7.
- Felsenstein S, Reiff AO, Ramanathan A. Transition of Care and Health-Related Outcomes in Pediatric-Onset Systemic Lupus Erythematosus. *Arthritis Care Res* 2015;67:1521–8.
- Kone-Paut I, Piram M, Guillaume S, et al. Lupus in adolescence. *Lupus* 2007;16:606–12.
- Lawson EF, Hersh AO, Trupin L, et al. Educational and vocational outcomes of adults with childhood- and adult-onset systemic lupus erythematosus: nine years of followup. *Arthritis Care Res* 2014;66:717–24.
- Son MB, Sergeyenko Y, Guan H, et al. Disease activity and transition outcomes in a childhood-onset systemic lupus erythematosus cohort. *Lupus* 2016;25:1431–9.
- Chira P, Ronis T, Ardoin S, et al. Transitioning youth with rheumatic conditions: perspectives of pediatric rheumatology providers in the United States and Canada. *J Rheumatol* 2014;41:768–79.
- Eleftheriou D, Isenberg DA, Wedderburn LR, et al. The coming of age of adolescent rheumatology. *Nat Rev Rheumatol* 2014;10:187–93.
- Hersh A. Growing up and moving on-transition of care for patients with childhood-onset rheumatic disease. *J Rheumatol* 2014;41:829–31.
- Hersh AO, Pang S, Curran ML, et al. The challenges of transferring chronic illness patients to adult care: reflections from pediatric and adult rheumatology at a US academic center. *Pediatr Rheumatol Online J* 2009;7:13.
- Hilderson D, Eyckmans L, Van der Elst K, et al. Transfer from paediatric rheumatology to the adult rheumatology setting: experiences and expectations of young adults with juvenile idiopathic arthritis. *Clin Rheumatol* 2013;32:575–83.
- Hilderson D, Moons P, Westhovens R, et al. Attitudes of rheumatology practitioners toward transition and transfer from pediatric to adult healthcare. *Rheumatol Int* 2012;32:3887–96.
- Lawson EF, Mellins ED. Paediatric rheumatic diseases: navigating the transition from paediatric to adult care. *Nat Rev Rheumatol* 2017;13:138–9.
- McDonagh JE. Transition of care from paediatric to adult rheumatology. *Arch Dis Child* 2007;92:802–7.
- Tattersall R, McDonagh JE. Transition: a rheumatology perspective. *Br J Hosp Med* 2010;71:315–9.
- Tucker LB, Cabral DA. Transition of the adolescent patient with rheumatic disease: issues to consider. *Rheum Dis Clin North Am* 2007;33:661–72.
- Wells CK, McMorris BJ, Horvath KJ, et al. Youth report of healthcare transition counseling and autonomy support from their rheumatologist. *Pediatr Rheumatol Online J* 2012;10:36.
- Eyckmans L, Hilderson D, Westhovens R, et al. What does it mean to grow up with juvenile idiopathic arthritis? A qualitative study on the perspectives of patients. *Clin Rheumatol* 2011;30:459–65.
- Hilderson D, Corstjens F, Moons P, et al. Adolescents with juvenile idiopathic arthritis: who cares after the age of 16? *Clin Exp Rheumatol* 2010;28:790–7.
- Luque Ramos A, Hoffmann F, Albrecht K, et al. Transition to adult rheumatology care is necessary to maintain DMARD therapy in young people with juvenile idiopathic arthritis. *Semin Arthritis Rheum* 2017;47:269–75.
- Mannion ML, Xie F, Baddley J, et al. Analysis of health care claims during the peri-transfer stage of transition from pediatric to adult care among juvenile idiopathic arthritis patients. *Pediatr Rheumatol Online J* 2016;14:49.
- McDonagh JE, first Ypeople. Young people first, juvenile idiopathic arthritis second: transitional care in rheumatology. *Arthritis Rheum* 2008;59:1162–70.
- McDonagh JE, Shaw KL, Southwood TR. Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *J Child Health Care* 2006;10:22–42.
- McDonagh JE, Southwood TR, Shaw KL, et al. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology* 2007;46:161–8.
- Minden K, Niewerth M, Listing J, et al. Long-term outcome in patients with juvenile idiopathic arthritis. *Arthritis Rheum* 2002;46:2392–401.
- Minden K KJ, Niewoerth M, Zink A. The health status of patients with juvenile idiopathic arthritis (JIA) significantly worsens after transfer from pediatric to adult care [abstract]. *Arthritis Rheum* 2014;66:1268–9.
- Robertson LP, McDonagh JE, Southwood TR, et al. Growing up and moving on. A multicentre UK audit of the transfer of adolescents with juvenile idiopathic arthritis from paediatric to adult centred care. *Ann Rheum Dis* 2006;65:74–80.
- Hersh AO, von Scheven E, Yazdany J, et al. Differences in long-term disease activity and treatment of adult patients with childhood- and adult-onset systemic lupus erythematosus. *Arthritis Rheum* 2009;61:13–20.
- Tucker LB, Uribe AG, Fernández M, et al. Adolescent onset of lupus results in more aggressive disease and worse outcomes: results of a nested matched case-control study within LUMINA, a multiethnic US cohort (LUMINA LVII). *Lupus* 2008;17:314–22.
- Amaral B, Murphy G, Ioannou Y, et al. A comparison of the outcome of adolescent and adult-onset systemic lupus erythematosus. *Rheumatology* 2014;53:1130–5.
- Livingston B, Bonner A, Pope J. Differences in clinical manifestations between childhood-onset lupus and adult-onset lupus: a meta-analysis. *Lupus* 2011;20:1345–55.
- Mina R, Brunner HI. Pediatric lupus—are there differences in presentation, genetics, response to therapy, and damage accrual compared with adult lupus? *Rheum Dis Clin North Am* 2010;36:53–80.
- González LA, Toloza SM, McGwin G, et al. Ethnicity in systemic lupus erythematosus (SLE): its influence on susceptibility and outcomes. *Lupus* 2013;22:1214–24.
- Brunner HI, Bishnoi A, Barron AC, et al. Disease outcomes and ovarian function of childhood-onset systemic lupus erythematosus. *Lupus* 2006;15:198–206.
- Gutiérrez-Suárez R, Ruperto N, Gastaldi R, et al. A proposal for a pediatric version of the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index based on the analysis of 1,015 patients with juvenile-onset systemic lupus erythematosus. *Arthritis Rheum* 2006;54:2989–96.
- Ruperto N, Buratti S, Duarte-Salazar C, et al. Health-related quality of life in juvenile-onset systemic lupus erythematosus and its relationship to disease activity and damage. *Arthritis Rheum* 2004;51:458–64.
- Hersh AO, Trupin L, Yazdany J, et al. Childhood-onset disease as a predictor of mortality in an adult cohort of patients with systemic lupus erythematosus. *Arthritis Care Res* 2010;62:1152–9.

52. Feldman CH, Collins J, Zhang Z, *et al.* Dynamic patterns and predictors of hydroxychloroquine nonadherence among Medicaid beneficiaries with systemic lupus erythematosus. *Semin Arthritis Rheum* 2018.
53. Mosley-Williams A, Lumley MA, Gillis M, *et al.* Barriers to treatment adherence among African American and white women with systemic lupus erythematosus. *Arthritis Rheum* 2002;47:630–8.
54. Knight AM, Trupin L, Katz P, *et al.* Depression risk in young adults with Juvenile- and Adult-Onset Lupus: twelve years of followup. *Arthritis Care Res* 2018;70:475–80.
55. Johnson SB, Blum RW, Giedd JN. Adolescent maturity and the brain: the promise and pitfalls of neuroscience research in adolescent health policy. *J Adolesc Health* 2009;45:216–21.
56. Steinberg L. Cognitive and affective development in adolescence. *Trends Cogn Sci* 2005;9:69–74.
57. Mickley KL, Burkhart PV, Sigler AN. Promoting normal development and self-efficacy in school-age children managing chronic conditions. *Nurs Clin North Am* 2013;48:319–28.
58. Suris JC, Michaud PA, Viner R. The adolescent with a chronic condition. Part I: developmental issues. *Arch Dis Child* 2004;89:938–42.
59. Yoos L. Chronic childhood illnesses: developmental issues. *Pediatr Nurs* 1987;13:25–8.
60. González LA, Toloza SM, Alarcón GS. Impact of race and ethnicity in the course and outcome of systemic lupus erythematosus. *Rheum Dis Clin North Am* 2014;40:433–54.
61. Demas KL, Costenbader KH. Disparities in lupus care and outcomes. *Curr Opin Rheumatol* 2009;21:102–9.
62. Uribe AG, Alarcón GS. Ethnic disparities in patients with systemic lupus erythematosus. *Curr Rheumatol Rep* 2003;5:364–9.
63. Roberts AL, Malspeis S, Kubzansky LD, *et al.* Association of Trauma and Posttraumatic Stress Disorder With Incident Systemic Lupus Erythematosus in a Longitudinal Cohort of Women. *Arthritis Rheumatol* 2017;69:2162–9.
64. Williams EM, Bruner L, Adkins A, *et al.* I too, am America: a review of research on systemic lupus erythematosus in African-Americans. *Lupus Sci Med* 2016;3:e000144.
65. Krishnan E, Hubert HB. Ethnicity and mortality from systemic lupus erythematosus in the US. *Ann Rheum Dis* 2006;65:1500–5.
66. Son MB, Johnson VM, Hersh AO, *et al.* Outcomes in hospitalized pediatric patients with systemic lupus erythematosus. *Pediatrics* 2014;133:e106–e113.
67. Baker K, Pope J. Employment and work disability in systemic lupus erythematosus: a systematic review. *Rheumatology* 2009;48:281–4.
68. McDonagh JE, Shaw KL. Adolescent rheumatology transition care in the UK. *Pediatr Ann* 2012;41:e8–e15.
69. Ammerlaan JW, Scholtus LW, Bijlsma HJ, *et al.* An urge for change: transitional care for young adults with juvenile idiopathic arthritis. *Patient Educ Couns* 2013;92:127–9.
70. Clemente D, Leon L, Foster H, *et al.* Systematic review and critical appraisal of transitional care programmes in rheumatology. *Semin Arthritis Rheum* 2016;46:372–9.
71. Hilderson D, Moons P, Van der Elst K, *et al.* The clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: results of the DON'T RETARD project. *Rheumatology* 2016;55:133–42.
72. Hilderson D, Westhovens R, Wouters C, *et al.* Rationale, design and baseline data of a mixed methods study examining the clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: the DON'T RETARD project. *BMJ Open* 2013;3:e003591.
73. Rettig P, Athreya BH. Adolescents with chronic disease. Transition to adult health care. *Arthritis Care Res* 1991;4:174–80.
74. Stringer E, Scott R, Mosher D, *et al.* Evaluation of a rheumatology transition clinic. *Pediatr Rheumatol Online J* 2015;13:22.
75. Tattersall RS. The MAGICC and practical approach to rheumatology transition. *Br J Hosp Med* 2012;73:552–7.
76. Tucker LB, Cabral DA. Transition of the adolescent patient with rheumatic disease: issues to consider. *Pediatr Clin North Am* 2005;52:641–52.
77. Nagra A, McGinnity PM, Davis N, *et al.* Implementing transition: ready steady go. *Arch Dis Child Educ Pract Ed* 2015;100:313–20.
78. McDonagh JE, Hackett J, McGee M, *et al.* The evidence base for transition is bigger than you might think. *Arch Dis Child Educ Pract Ed* 2015;100:321–2.
79. Campbell F, Biggs K, Aldiss SK, *et al.* Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database Syst Rev* 2016;4:CD009794.
80. Chu PY, Maslow GR, von Isenburg M, *et al.* Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *J Pediatr Nurs* 2015;30:e19–e27.
81. Rachas A, Lefevre D, Meyer L, *et al.* Evaluating continuity during transfer to adult care: a systematic review. *Pediatrics* 2016;138:e20160256.
82. Gabriel P, McManus M, Rogers K, *et al.* Outcome evidence for structured pediatric to adult health care transition interventions: a systematic review. *J Pediatr* 2017;188:263–9.
83. Hollander MC, Sage JM, Greenler AJ, *et al.* International consensus for provisions of quality-driven care in childhood-onset systemic lupus erythematosus. *Arthritis Care Res* 2013;65:1416–23.
84. McDonagh JE. Growing up and moving on: transition from pediatric to adult care. *Pediatr Transplant* 2005;9:364–72.
85. Groot N, de Graeff N, Avcin T, *et al.* European evidence-based recommendations for diagnosis and treatment of childhood-onset systemic lupus erythematosus: the SHARE initiative. *Ann Rheum Dis* 2017;76:1788–96.
86. Brunner HI, Huggins J, Klein-Gitelman MS. Pediatric SLE--towards a comprehensive management plan. *Nat Rev Rheumatol* 2011;7:225–33.
87. Calvo I, Antón J, Bustabad S, *et al.* Consensus of the Spanish society of pediatric rheumatology for transition management from pediatric to adult care in rheumatic patients with childhood onset. *Rheumatol Int* 2015;35:1615–24.
88. Fair C, Cuttance J, Sharma N, *et al.* International and interdisciplinary identification of health care transition outcomes. *JAMA Pediatr* 2016;170:205–11.
89. Suris JC, Akre C. Key elements for, and indicators of, a successful transition: an international Delphi study. *J Adolesc Health* 2015;56:612–8.
90. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, *et al.* Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2011;128:182–200.
91. Akre C, Suris JC, Belot A, *et al.* Building a transitional care checklist in rheumatology: A Delphi-like survey. *Joint Bone Spine* 2018;85:435–440.
92. Kieckhefer GM, Trahms CM. Supporting development of children with chronic conditions: from compliance toward shared management. *Pediatr Nurs* 2000;26:354–63.
93. Barlow J, Wright C, Sheasby J, *et al.* Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns* 2002;48:177–87.
94. Lawson EF, Hersh AO, Applebaum MA, *et al.* Self-management skills in adolescents with chronic rheumatic disease: a cross-sectional survey. *Pediatr Rheumatol Online J* 2011;9:35.
95. Barlow JH, Turner AP, Wright CC. A randomized controlled study of the Arthritis Self-Management Programme in the UK. *Health Educ Res* 2000;15:665–80.
96. Taylor G. Tips for managing young adult rheumatology patients. *The Rheumatologist* 2017;11:51–4.
97. Tong A, Jones J, Craig JC, *et al.* Children's experiences of living with juvenile idiopathic arthritis: a thematic synthesis of qualitative studies. *Arthritis Care Res* 2012;64:1392–404.
98. Bingham CA, Scalzi L, Groh B, *et al.* An assessment of variables affecting transition readiness in pediatric rheumatology patients. *Pediatr Rheumatol Online J* 2015;13:42.
99. Wood DL, Sawicki GS, Miller MD, *et al.* The Transition Readiness Assessment Questionnaire (TRAQ): its factor structure, reliability, and validity. *Acad Pediatr* 2014;14:415–22.
100. Transition Readiness Assessment Questionnaire 5.0. <https://www.rheumatology.org/Portals/0/Files/Transition-Readiness-Assessment-Questionnaire.pdf> (accessed 12 Jul 2018).
101. Got Transition. Transition Readiness. <https://www.gottransition.org/resourceGet.cfm?id=224> (accessed 12 Jul 2018).
102. Rheumatology ACo. Pediatric to Adult Rheumatology Care Transition. <https://www.rheumatology.org/Practice-Quality/Pediatric-to-Adult-Rheumatology-Care-Transition> (accessed 12 Jul 2018).
103. Shaw KL, Southwood TR, McDonagh JE, *et al.* Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a postal survey. *Rheumatology* 2004;43:211–9.
104. Sharma N, O'Hare K, O'Connor KG, *et al.* Care Coordination and Comprehensive Electronic Health Records are Associated With Increased Transition Planning Activities. *Acad Pediatr* 2018;18:111–8.
105. Got Transition. Health Care Transition Resources. <https://www.gottransition.org/providers/index.cfm> (accessed 12 Jul 2018).
106. Annunziato RA, Baisley MC, Arrato N, *et al.* Strangers headed to a strange land? A pilot study of using a transition coordinator

- to improve transfer from pediatric to adult services. *J Pediatr* 2013;163:1628–33.
107. Wright J, Elwell L, McDonagh JE, *et al.* Parents in transition: experiences of parents of young people with a liver transplant transferring to adult services. *Pediatr Transplant* 2017;21:e12760.
 108. Suris JC, Larbre JP, Hofer M, *et al.* Transition from paediatric to adult care: what makes it easier for parents? *Child Care Health Dev* 2017;43:152–5.
 109. Wright J, Elwell L, McDonagh JE, *et al.* "Are these adult doctors gonna know me?" Experiences of transition for young people with a liver transplant. *Pediatr Transplant* 2016;20:912–20.
 110. Yazdany J, Panopalis P, Gillis JZ, *et al.* A quality indicator set for systemic lupus erythematosus. *Arthritis Rheum* 2009;61:370–7.
 111. Koneru S, Shishov M, Ware A, *et al.* Effectively measuring adherence to medications for systemic lupus erythematosus in a clinical setting. *Arthritis Rheum* 2007;57:1000–6.
 112. Feldman CH, Yazdany J, Guan H, *et al.* Medication nonadherence is associated with increased subsequent acute care utilization among Medicaid beneficiaries with systemic lupus erythematosus. *Arthritis Care Res* 2015;67:1712–21.
 113. Feldman CH CJ, Zhang Z, Kawachi I. Azathioprine and mycophenolate mofetil adherence in a nationwide Medicaid cohort with systemic lupus erythematosus [abstract]. *Arthritis Rheum* 2016;68.
 114. Alsowaida N, Alrasheed M, Mayet A, *et al.* Medication adherence, depression and disease activity among patients with systemic lupus erythematosus. *Lupus* 2018;27:327–32.
 115. Duvdevany I, Cohen M, Minsker-Valtzer A, *et al.* Psychological correlates of adherence to self-care, disease activity and functioning in persons with systemic lupus erythematosus. *Lupus* 2011;20:14–22.
 116. Julian LJ, Yelin E, Yazdany J, *et al.* Depression, medication adherence, and service utilization in systemic lupus erythematosus. *Arthritis Rheum* 2009;61:240–6.
 117. Nguyen E, Bugno L, Kandah C, *et al.* Is there a good app for that? Evaluating m-Health apps for strategies that promote pediatric medication adherence. *Telemed J E Health* 2016;22:929–37.
 118. Koneru S, Kocharla L, Higgins GC, *et al.* Adherence to medications in systemic lupus erythematosus. *J Clin Rheumatol* 2008;14:195–201.
 119. Nieuwlaat R, Wilczynski N, Navarro T, *et al.* Interventions for enhancing medication adherence. *Cochrane Database Syst Rev* 2014(11):CD000011.
 120. Dalebout GM, Broadbent E, McQueen F, *et al.* Intentional and unintentional treatment nonadherence in patients with systemic lupus erythematosus. *Arthritis Care Res* 2011;63:342–50.
 121. Ryan R, Santesso N, Lowe D, *et al.* Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews. *Cochrane Database Syst Rev* 2014(4):CD007768.
 122. Farinha F, Freitas F, Águeda A, *et al.* Concerns of patients with systemic lupus erythematosus and adherence to therapy - a qualitative study. *Patient Prefer Adherence* 2017;11:1213–9.
 123. Scalzi LV, Hollenbeak CS, Mascuilli E, *et al.* Improvement of medication adherence in adolescents and young adults with SLE using web-based education with and without a social media intervention, a pilot study. *Pediatr Rheumatol Online J* 2018;16:18.
 124. Sadun RE, Schanberg LE. Using social media to promote medication adherence. *Nat Rev Rheumatol* 2018:445–.