RHEUMATOLOGY NURSE
PRACTICE
Accredited education for registered nurses and advanced practice providers

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VOLUME 5 / ISSUE 3

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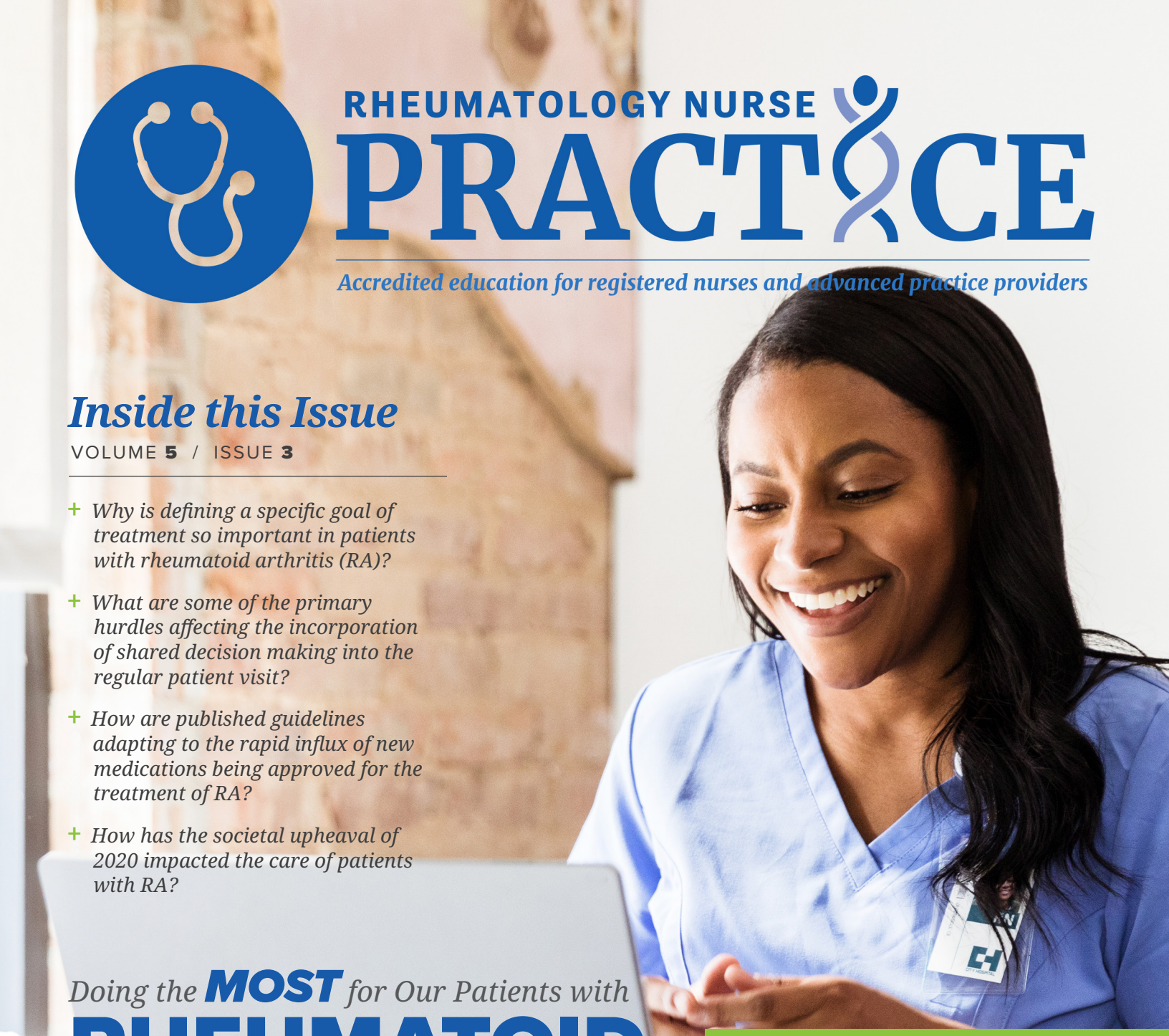

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RHEUMATOID ARTHRITIS

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TARGET AUDIENCE

This activity has been designed to meet the educational needs of nurses, nurse practitioners, and physician assistants. Other healthcare providers may also participate.

ACTIVITY DESCRIPTION

This issue of *Rheumatology Nurse Practice* will focus on some of the most recent data concerning best practices for the management of rheumatoid arthritis and offer a variety of helpful tools to help build providers' confidence. We'll also examine treatment guidelines, review validated online resources, and provide a roadmap for how this information can translate into clinical practice.

LEARNING OBJECTIVES

After participating in the activity, learners should be better able to:

- Define the term "shared decision making" and explain its importance in the management of patients with rheumatoid arthritis (RA)
- Analyze published guideline recommendations regarding first- and second-line treatment of RA
- Differentiate between the terms "cycling" and "swapping" as it relates to adjusting therapy in patients with RA
- Determine when it may and may not be appropriate to taper disease-modifying anti-rheumatic therapy in patients with RA who reach set treatment targets

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RHEUMATOID ARTHRITIS

Through use of an evidence-based treatment strategy, 75-80% of today's patients with rheumatoid arthritis (RA) can now achieve remission or low disease activity.[1] This is a huge advance. Whereas a diagnosis of RA once represented a future likely marked by increasing levels of disability, most patients today can work with their providers to find a treatment plan that allows them to go about their normal lives without accommodations. Indeed, thanks to an ever-growing pool of effective disease-modifying anti-rheumatic drugs (DMARDs) with different modes of action, it is more likely than ever that an individual with RA will reach their treatment target, preserving their physical function and quality of life.[2,3]

This doesn't mean there aren't challenges to today's treatment of patients with RA. Although the variety of DMARDs currently available means that patients have many options if one or multiple drug classes don't work well to control their symptoms, having so many choices can sometimes feel intimidating to healthcare providers. For any given patient, clinicians must choose between monotherapy or combination therapy with conventional synthetic, biologic, or small molecule DMARDs, and then determine within each category of drug which option will be best. Providers must also determine how long to wait for a response before adjusting a patient's treatment plan and then decide what sort of adjustment is needed. Not surprisingly, the complexity of the current RA treatment landscape can make it difficult for clinicians to feel confident they are delivering the best quality care to their patients.

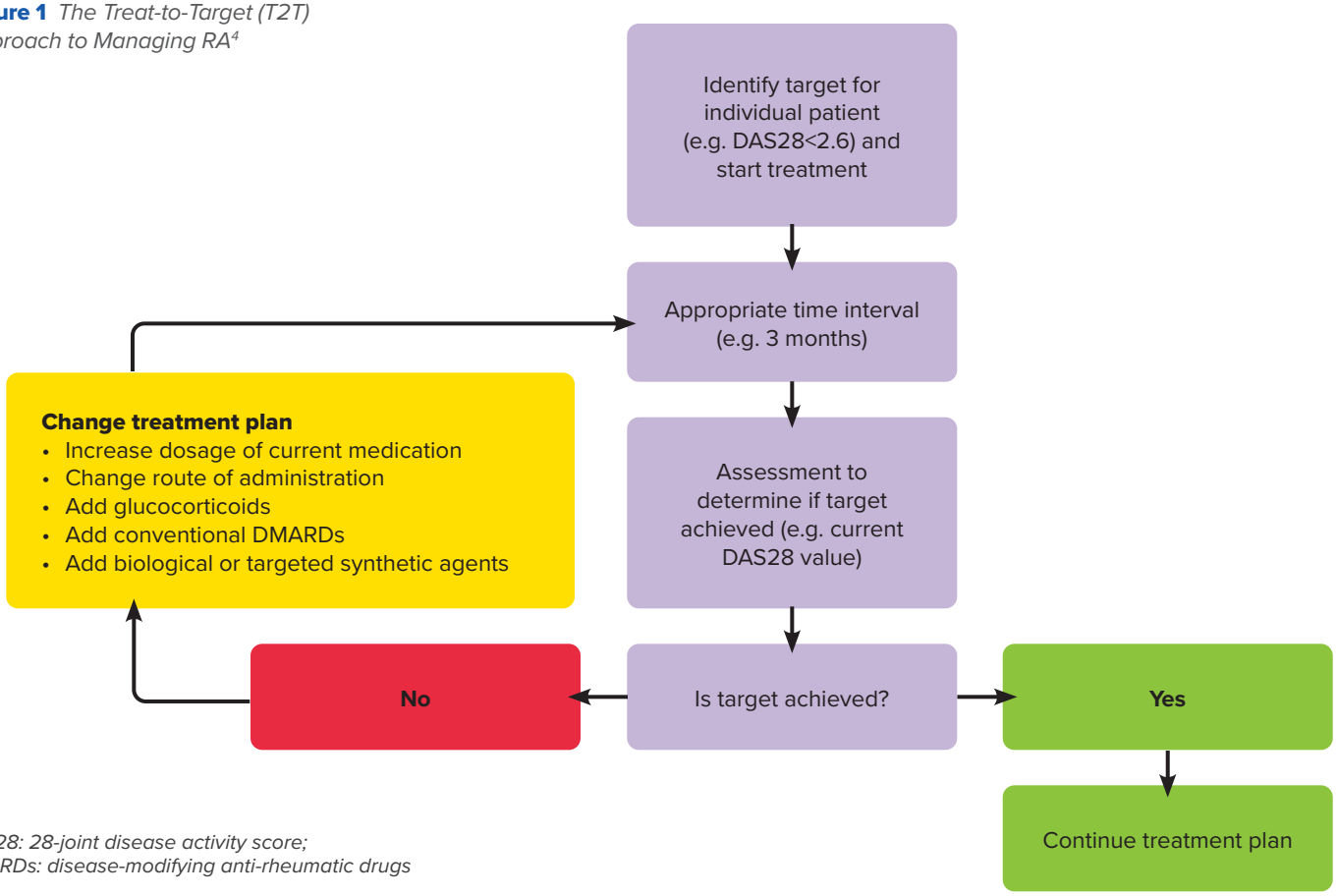
Setting Treatment Goals

Since the "treat-to-target," or T2T, approach for managing RA was introduced in 2010, it has been endorsed by the American College of Rheumatology (ACR), the European League Against Rheumatism (EULAR), and other related professional organizations worldwide.[4] The T2T approach aims to help patients achieve a defined treatment target as quickly as possible, using shared decision making (SDM) to determine the ultimate treatment goal and figure out how best to achieve it. Using this strategy, providers regularly assess patients' disease activity using a composite measure that includes joint counts such as the 28-joint disease activity score (DAS28), simple disease activity index (SDAI), or clinical disease activity index (CDAI) (Figure 1).[5] If acceptable progress toward the treatment target is not achieved within 3 months of initiation of a specific treatment regimen, a patient's treatment plan is modified, with the goal to reach the predetermined target within 6 months of treatment initiation.[1]

Of note, the word "target" in T2T has sometimes proven confusing; prescribing a targeted RA therapy (ie, one that "targets" key molecules in RA pathogenesis, such as tumor necrosis factor [TNF] or Janus kinase [JAK]), does not necessarily imply that the T2T approach is being used, and using the T2T approach does not necessarily imply that targeted therapies are being used.[4] The "target" is merely the goal of therapy.

In T2T, the treatment target is typically either remission or low disease activity, both of which are defined by different cutoffs within the selected composite measure of RA severity.[6] Some evidence suggests that when providers select a more aggressive goal of remission as the treatment target, a patient is more likely to achieve that goal than when low disease activity is the predetermined target, although this does not seem to translate into better physical functioning.[6] In practice, the choice of treatment target is often influenced by a patient's unique characteristics, such as comorbidities or drug-associated risks. Most providers aim to select the

Figure 1 *The Treat-to-Target (T2T) Approach to Managing RA*[4]



DAS28: 28-joint disease activity score;
DMARDs: disease-modifying anti-rheumatic drugs

treatment plan that offers the most favorable risk/benefit ratio in a given scenario.[4,5] In addition, some experts may feel more comfortable selecting low disease activity as a treatment target if a patient's disease is unlikely to cause irreversible damage (for example, if their RA is seronegative, non-erosive, or not highly active).[4]

Multiple studies have shown that, compared to standard care, the T2T approach results in higher rates of remission and better quality of life for RA patients.[4,7] Indeed, T2T allows up to 50% of RA patients to achieve remission.[1] Despite compelling evidence, however, many patients are still not benefitting from the T2T approach. For example, in a recent study of 651 U.S. patients with RA receiving care from 46 providers at 11 different sites, 64% of office visits featured none of the components of the T2T approach (eg, recording a disease target, recording a disease activity measure, engaging in shared decision-making, and changing treatment if a patient was not at their disease target), and only 0.3% of visits featured all of the T2T components.[8] These findings suggest that much room for improvement still exists, and greater adoption of the T2T strategy could result in better outcomes for patients with RA.

Importance of Shared Decision Making

SDM is a core component of the T2T approach. In fact, EULAR's first overarching principle for managing RA states that, "Treatment of patients with RA should aim at the best care and must be based on a shared decision between the patient and the rheumatologist."[2] But what exactly does SDM look like in RA care, and why is it so important?

In general, SDM has been defined as "an approach where clinicians and patients make decisions together using the best available evidence."[9] In addition to respecting patient autonomy, SDM has been shown to lead to a number of desirable outcomes, such as greater patient engagement and reduced healthcare costs.[9] Active engagement of patients in making decisions about their own health is a key component of patient-centered care,[10] one of the fundamental approaches espoused by the Institute of Medicine for improving the quality of healthcare in the United States.[11]

When practicing SDM, clinicians collaborate with patients to provide care that is informed by the best available evidence while also reflecting a patient's values and preferences.[12] SDM is essential for the success of the T2T approach, as patient and provider must work together to choose a treatment goal, assess progress toward that goal, and make important decisions about how to reach the target.[12] Clinicians often report that patients' preferences and knowledge of RA medications are key limiting factors to implementing T2T.[12] Patient education, which is a critical component of SDM, can help address these issues. In turn, clinicians should be aware that patients may have important goals that are not explicitly captured in the T2T paradigm; for example, patients may possess highly personal treatment goals involving social and sexual functioning, the ability to work, or maximizing overall well-being.[13] Thus, it is essential that providers initiate conversations with their patients about what successful treatment means to them and then provide the basic education that patients need to engage in SDM conversations about their treatment plans.

For patients with autoimmune diseases such as RA, SDM is associated with greater likelihood of adherence to and satisfaction with their treatment plan.[14] This is meaningful, as non-adherent patients experience RA flares 3.7 times more often than adherent patients.[15] Even so, research suggests that SDM is currently only used at a low to moderate level in the treatment of RA.[16] One reason for this low uptake is that many clinicians believe that engaging in SDM will take up an unacceptable amount of time during already busy office visits or is too complicated to implement.[17] Patient education materials and decision aids can help address these issues by facilitating conversations about key topics such as medication contraindications, cost, time to patient response, administration route and dosing frequency, and side effects (Figure 2).[12]

Figure 2 *Shared Decision Making Tools*

Questions to ask patients:

When selecting a treatment target

- What are your goals for treatment?
- What would successful treatment look like to you?

When selecting a treatment plan

- Are you considering pregnancy?
- Do you drink alcohol?
- Do you have active tuberculosis, or have you been exposed to someone with tuberculosis?
- Do you have liver disease?
- What other medications are you taking?
- Are you worried that paying for your medication will be difficult?
- How important is it to you that a medication provides rapid relief of symptoms?
- Would you prefer a once or twice daily pill, or are less frequent injections or infusions a better option for you?
- Would you prefer injections you can perform at home or infusions that require you to come in for a visit?
- How often do you exercise each week? What kinds of physical activities do you enjoy?
- What is your diet like? Can you describe what you eat in a typical day?

Figure 2 continues on page 6

Figure 2 *Shared Decision Making Tools*
(Continued from page 5)

After a treatment plan has been initiated

- Have you noticed any changes in your symptoms since your last visit?
- Are you experiencing any side effects from your medication?
- Are you experiencing difficulty obtaining or paying for your medication?
- Are you experiencing any challenges in taking your medication as directed?
- Are you happy with your progress on this treatment plan so far? Do you feel closer to your treatment goal?
- What kind of exercise have you been doing lately?
- What has your diet been like lately?

Patient Education Resources

- University of California San Francisco's RA Medication Summary Guide for Patients: "Your Guide to Rheumatoid Arthritis Medicines" (English, Spanish, Chinese printouts
- UpToDate's Beyond the Basics Series (English; longer, more detailed articles)
  - RA Symptoms and Diagnosis
  - RA Treatment
  - Disease-modifying Antirheumatic Drugs (DMARDs) in RA
  - Complementary and Alternative Therapies for RA
  - RA and Pregnancy

Decision Aids

- University of California San Francisco's RA Choice Decision Aid (English, Spanish printouts)
- ANSWER-2 Decision Aid (English, interactive and web-based, designed for patients considering biologics)

Initiating RA Treatment

Treating RA as soon as the disease is diagnosed is key to optimizing patient outcomes. Even before the clinical signs of RA appear, multiple pathologic mechanisms begin within a patient's joints.[18] Bone erosions can be detected in approximately 25% of individuals with RA within 3 months of symptom onset.[19] Therefore, even seemingly small delays in initiating treatment can result in a therapeutic window of opportunity being missed. In one recent study, for example, patients who were seen by a rheumatologist within 6 weeks of RA symptom onset were 2.5 times more likely to achieve sustained drug-free remission than patients seen 7 to 12 weeks after symptom onset.[20] Because early treatment can prevent or slow joint damage in up to 90% of patients with RA, thereby helping them avoid permanent disability,[1] EULAR guidelines recommend that therapy with DMARDs start as soon as the disease is diagnosed.[2]

The recently-updated EULAR guidelines (the most recent ACR guidelines for the treatment of RA are >5 years old) recommend that the first RA treatment strategy include methotrexate (MTX), a standard anchor of therapy for decades.[2] MTX is effective as both monotherapy and in combination with glucocorticoids, other conventional DMARDs, or biologic or small molecule DMARDs. Studies have shown that 40-50% of patients with RA will achieve remission or low disease activity through treatment with MTX and short-term glucocorticoids alone.[1]

MTX has many attractive features, including a manageable safety profile, the ability to be titrated over a large dose range, both oral and parenteral administration routes, and a cost-effective nature.[5] Typically, MTX is initiated at a dose predicted to be well-tolerated, in combination with bridging glucocorticoids to provide more rapid symptom relief. The dose is then titrated up as necessary.[5] In general, it takes roughly 6 months for a patient to see a full response to MTX; in patients with an inadequate response or intolerance to oral MTX, parenteral administration should be considered.[5]

To date, no study has shown that first-line therapy with biologic DMARDs plus MTX is superior to therapy with MTX plus glucocorticoids in patients with RA; first-line therapy with small molecule DMARDs has not yet been compared to therapy with MTX plus glucocorticoids.[2] Thus, unless a contraindication for MTX is present, EULAR guidelines recommend that first-line therapy for patients with RA should consist of MTX plus short-term glucocorticoids.[2] Recent practice, however, does not necessarily adhere to this recommendation: in the United States, 36% of patients received a biologic as their first-line RA therapy in 2012, up from 27% in 2009.[21] For patients with a contraindication or early intolerance to methotrexate, EULAR guidelines recommend that alternative conventional DMARDs (eg, leflunomide, sulfasalazine) be considered as part of the first-line treatment strategy alongside short-term glucocorticoids.[2]

When to Use Biologic or Small Molecule DMARDs

EULAR guidelines recommend that if a patient does not achieve their treatment target with their first conventional DMARD strategy AND poor prognostic factors such as persistently high disease activity are present (Figure 3), a biologic or small molecule DMARD should be added to the treatment plan.[2] If the treatment target is not achieved with the first conventional DMARD strategy and no poor prognostic factors are present, other conventional DMARDs should instead be considered.

Currently, a wide array of biologic and small molecule DMARDs are available (Table 1). Whereas biologic DMARDs are large, complex proteins that target specific extracellular mediators in the inflammatory cascade leading to RA symptoms, JAK inhibitors (the only currently available small molecule DMARDs) are much smaller molecules that are able to penetrate cells and thus alter intracellular signaling involved in the inflammatory cascade.

At present, there is unfortunately no straightforward way to determine which biologic or small molecule DMARD will elicit the best response from a given patient. Moreover, EULAR has concluded that no compelling comparative effectiveness data exists that may help providers select one agent or class of agents over another.[2] These realities can make selecting a biologic or small molecule DMARD feel overwhelming at times.

There are some attributes that can potentially be teased out during a SDM conversation that may help guide the decision, such as dosing schedules and route of administration. Some patients, for example, may prefer to take a pill once or twice a day, making JAK inhibitors the best choice for them; other patients may prefer weekly injections or even less frequent infusions, making biologics a better choice. In addition, whereas some patients prefer biologics that can be self-administered at home via injections, others prefer facility-administered infusions. Adherence is also a consideration—patients who anticipate or experience trouble remembering to take a daily JAK inhibitor may be better suited to a biologic with less frequent administration.[22]

A patient's insurance coverage may also determine DMARD choices. Some insurers may not cover specific agents at all, while granting others a "preferred" status that can result in much lower out of pocket costs for patients. In addition, many insurers are now specifying which therapies must be tried for what period of time before prescribing a biologic or small molecule DMARD.[23] Clinicians should keep in mind that because biologic and small molecule DMARDs are expensive, part of setting up patients for successful treatment involves ensuring that the therapy selected will not cause them an undue financial burden.

Whatever the biologic or small molecule DMARD selected, EULAR guidelines recommend that it be combined with a conventional DMARD such as MTX.[2] Research shows that all biologic and small molecule DMARDs have at least equivalent and typically greater efficacy when combined with conventional DMARDs, and up to 75% of patients treated with this type of combination therapy are able to reach their treatment target.[1] Unfortunately, many patients are not receiving guideline-consistent care in this area. For example, among patients with RA who received oral MTX first followed by a subsequent biologic DMARD in 2012, only 45% continued to receive MTX along with the biologic; this was a substantial decrease from 74% in 2009.[21] Up to 40% of patients with RA are currently receiving biologic DMARD monotherapy.[2] For patients who cannot be treated with conventional DMARDs because of contraindications or other factors, EULAR guidelines specify that IL-6 pathway inhibitors (sarilumab and tocilizumab) and small molecule DMARDs (the JAK inhibitors baricitinib, tofacitinib, and upadacitinib) may have some advantages over the non-IL-6 pathway inhibitor biologic DMARDs as monotherapy.[2]

Figure 3

Poor RA Prognostic Factors[2]

- Persistently moderate or high disease activity according to composite measures that include joint counts despite conventional DMARD therapy
- High acute phase reactant levels
- High swollen joint counts
- Presence of rheumatoid factor (RF) and/or anti–citrullinated protein antibodies (ACPAs), especially at high levels
- Presence of early erosions
- Failure of 2 or more conventional DMARDs

Minimizing Toxicity and Maximizing Tolerability

Although DMARDs play an essential role in helping patients achieve remission or low disease activity, they are often accompanied by adverse effects (AEs) that reduce patients' quality of life, sometimes even leading them to abandon a particular therapy. Fortunately, providers can often help prevent AEs from occurring in the first place or manage them promptly and effectively when they do arise.

Table 1 *FDA-approved Biologic and Small Molecule DMARDs*

Type	Molecular Target	Agents	Administration[a]
Biologic	TNF	Adalimumab	Injection every 1-2 weeks
		Certolizumab	Injection every 2-4 weeks
		Etanercept	Injection every 1-2 weeks
		Golimumab	Injection once a month OR Infusion every 4-8 weeks
		Infliximab	Injection every 2-8 weeks
	IL-6 receptor	Sarilumab	Injection every 2 weeks
		Tocilizumab	Injection every 1-2 weeks OR Infusion every 4 weeks
	CD80/86	Abatacept	Injection every week OR Infusion every 2-4 weeks
	CD20	Rituximab	Infusion 4 times a year (2 infusions separated by 2 weeks, twice a year)
Small molecule	JAK	Baricitinib	Oral, once daily
		Tofacitinib	Oral, once or twice daily
		Upadacitinib	Oral, once daily

[a]*Administration frequency typically decreases once a patient has reached the maintenance phase or as they progress in therapy*

For example, many of the most common AEs related to MTX (such as nausea, stomach pain, stomatitis, and anemia) result from the medication's inhibition of folate acid metabolism. Thus, counseling patients to take daily folic acid supplements is key to preventing these AEs.[24] Counseling patients to take their pills with food can also ease gastrointestinal symptoms, as can switching from pills to the injectable formulation of the medication.[25]

A major risk associated with the use of biologic and small molecule DMARDs, which suppress the immune system, is infection.[2] Therefore, EULAR guidelines recommend that patients be brought up to date on their vaccinations before initiating therapy with these DMARDs, though non-live vaccines can be administered to patients even after they begin DMARD therapy (Figure 4).[26] Of note, vaccination is another aspect of RA treatment in which SDM is essential,[26] as patients often have questions about the efficacy and safety of vaccines and want to play an active role in determining which vaccines to receive. Currently, the rate of referral for vaccines is low for RA patients,[26] making paying greater attention to patients' vaccination status an easy way for clinicians to improve the chance of treatment success.

Though these are some of the most common AEs associated with DMARDs, the problems that can arise during treatment are many and varied. Therefore, clinicians must be alert for myriad potential issues. Throughout treatment, providers can make an effort to nurture strong alliances and regularly inquire about common AEs so that patients feel comfortable discussing any challenges they encounter with their therapies. In this way, clinicians can ensure they are able to respond swiftly when AEs do arise, whether by adjusting a patient's dose, switching a medication, or finding another appropriate solution.

Deciding When to Cycle or Swap

Many patients with RA will need to try several therapies before finding the one that allows them to reach their treatment target. In fact, one of EULAR's overarching principles for managing RA is that "patients require access to multiple drugs with different modes of action to address the heterogeneity of RA; they may require multiple successive therapies throughout life."[2] Indeed, up to half of patients starting a new DMARD will stop

it within 12-18 months because of insufficient efficacy or AEs.[2] Therefore, providers must be prepared to be flexible when accompanying a patient along their treatment journey.

To gauge progress toward the treatment target, EULAR guidelines recommend that providers monitor patients with active RA every 1-3 months using a selected composite measure of disease severity; if there is no improvement by 3 months, or the target has not been reached by 6 months, a patient's therapy should be adjusted.[2] Research has shown that if a patient's disease activity does not improve by at least 50% within 3 months, their probability of achieving remission or low disease activity on that therapy is low.[27,28] If adjusting the dose or administration of a patient's current therapy does not result in sufficient improvement, providers must choose between **cycling** (switching within a drug class; from one TNF inhibitor to another, for example) and **swapping** (switching between drug classes, to an agent with a different mode of action).

No definitive strategy for choosing whether to cycle or swap has yet been established. Evidence exists to support both approaches, and no head-to-head trials have shown that one is superior to the other.[29,30] Even after one agent in a class fails, a different agent in the same class can be effective due to differences in the drugs' biochemical structures and properties, immunogenicity, or bioavailability.[29] Therefore, EULAR guidelines recommend that if a patient has failed to reach their treatment target on one or more biologic or small molecule DMARDs, treatment with another biologic or small molecule should be considered.[2]

The first biologic DMARD that most patients receive will be a TNF inhibitor.[29,31] TNF inhibitors were the first biologics to be developed for RA and have become the most frequently prescribed class of biologics for patients who have failed to reach their treatment target using conventional DMARDs.[32] However, roughly 30-40% of patients who begin a TNF inhibitor will discontinue it due to primary failure, secondary loss of response, or tolerability issues.[29] Therefore, providers must be comfortable responding when a patient's first TNF inhibitor does not allow them to make adequate progress toward their treatment target. The five TNF inhibitors currently available to treat RA vary by molecular structure, half-life, administration route, dosing interval, immunogenicity, and suitability for use in women who wish to become pregnant.[29] Research shows that some patients respond to one TNF inhibitor but not another, although the chances of achieving a preset treatment target decreases with every successive TNF inhibitor initiated.[33] On the basis of existing evidence, EULAR guidelines recommend that if one TNF inhibitor therapy has failed, patients may receive a second TNF inhibitor (cycling) OR an agent with another mode of action (swapping).[2] However, some experts, including those who created the ACR guidelines for the treatment of RA, believe that the available data, though low-quality, favors swapping to an agent with a different mode of action.[34,35] Whichever strategy is chosen, guidelines suggest that MTX should ideally be continued alongside the new biologic or small molecule DMARD. Conventional DMARD triple therapy (consisting of MTX plus hydroxychloroquine and sulfasalazine) may also be considered.[35]

Other considerations may also affect the decision to cycle or swap, including whether the DMARD that has failed is a TNF inhibitor or another type of medication. Swapping options may be limited when certain agents are contraindicated for a patient, perhaps because of comorbidities. For example, a patient with a history of serious infections or thrombosis might be at greater risk of these complications if a JAK inhibitor is prescribed, and a patient with chronic obstructive pulmonary disease may be at greater risk of complications if the CD80/86 inhibitor abatacept is prescribed.[35] Other factors, such as a patient's preferred frequency and mode of administration and insurance coverage, may also help determine the sequence of agents prescribed as explored in the earlier discussion about selecting a patient's first biologic or small molecule DMARD. In the future, head-to-head trials of cycling vs. swapping may provide additional insight into how to sequence therapies to provide the best outcomes for patients.

Figure 4

EULAR Vaccination Recommendations for Patients with RA[26]

- **Influenza** and **pneumococcal** vaccinations should be strongly considered for the majority of patients
- **Tetanus** and **human papillomavirus (HPV)** vaccinations should be administered in accordance with recommendations for the general population
- **Hepatitis A and B** vaccinations should be administered to patients at risk (for example, patients who are at high risk of exposure to the hepatitis B virus due to occupation, household contacts, sexual partners, or IV drug use)
- **Herpes zoster** vaccination should be considered for patients at high risk
- **Yellow fever** vaccination should generally be avoided
- Immunocompetent household members should be encouraged to receive vaccines according to national guidelines, except for oral polio vaccines
- Live attenuated vaccines should be avoided during the first 6 months of life in newborns of mothers treated with biologic DMARDs during the second half of pregnancy

Achieving Remission: What Now?

Fortunately, many current patients with RA are able to achieve long-lasting remission. When this happens, providers must be prepared to help them transition to a treatment plan that allows them to maintain their treatment target while minimizing the impact of therapy upon their lives. EULAR guidelines recommend that once a patient has achieved "persistent remission" (a term for which the organization acknowledges there is no clear definition) and glucocorticoids have been tapered, providers should consider tapering the dose of any biologic or small molecule DMARD, especially if those agents are being used in combination with a conventional DMARD such as MTX.[2] Tapering does not necessarily mean that a patient will ever entirely discontinue a medication but may instead involve dose reductions or lengthening the interval between administration, according to a given patient's needs. Tapering **is not** recommended for patients who have achieved low disease activity but not remission.[2] Because patients with joint damage are especially vulnerable to further progression upon complete withdrawal of DMARDs, providers must be especially cautious when helping these individuals formulate a maintenance plan.[2] However, clinicians may be reassured to learn that more than 80% of patients who discontinue biologics and subsequently experience flares are able to regain control of their disease by resuming their previous treatment.[2] Thus, providers should expect the process of trial and error to continue into the maintenance stage of treatment.

Some patients achieve remission on MTX or another conventional DMARD without ever having received a biologic or small molecule DMARD, while others successfully discontinue biologic or small molecule DMARDs and are able to maintain remission on conventional DMARD monotherapy alone. For those patients, EULAR guidelines recommend that clinicians consider tapering the dose of a patient's conventional DMARD.[2] In doing so, they should bear in mind that it is relatively rare for patients to be "cured" of RA; most will need continued therapy, and EULAR guidelines states that a drug that has proven efficacy in a patient and is well tolerated should not be discontinued.[2] However, many patients may be able to maintain their remission on lower doses of their conventional DMARD, minimizing toxicity threats and maximizing tolerability.

Although most patients are not able to achieve sustained, drug-free remission, this does occur, and we are learning more about how to predict which individuals have the best chance of reaching this state. Recently, results from the IMPROVED trial shed light on the importance of early remission in predicting a patient's likelihood of achieving sustained, drug-free remission.[36,37] This trial divided patients into two groups: those who (1) achieved remission early (within 4 months) after being treated with MTX and glucocorticoids, and (2) required escalated treatment with either conventional DMARD triple therapy or MTX plus adalimumab. Five years of follow-up data showed that among the patients who experienced early remission, 35% achieved sustained drug-free remission; among patients in the escalated treatment group, only 11% did. In addition, when both groups were combined, 37% of patients with anti-citrullinated protein antibody (ACPA)-negative status achieved sustained drug-free remission, whereas only 18% of ACPA-positive patients did so. Additional research is underway to learn more about clinical and biomarker data that can be used to predict which patients are most likely to achieve drug-free remission.[38] It is therefore possible that clinicians may soon feel more comfortable tapering and ultimately discontinuing therapy for selected patients who have achieved sustained remission on a conventional DMARD.

Conclusion

Providers are fortunate to have many DMARDs to choose from when treating patients with RA. The array of effective drugs, paired with the T2T approach, offers patients an unparalleled opportunity to achieve remission or low disease activity. Clinicians are still, however, tasked with promptly identifying the right therapy for the right patient. Once patients experience joint damage due to factors such as a delay in initiating treatment or languishing on an ineffective therapy, they may never be able to recover normal physical function, even if remission is later achieved.[1] Although the prospect of choosing the best therapies in the best order can feel intimidating, EULAR guidelines provide clinicians with a straightforward framework for making clinical decisions alongside their patients. The complex therapeutic landscape for RA will no doubt continue to evolve; novel therapies targeting IL-6, JAK, and the granulocyte-macrophage colony-stimulating factor receptor-alpha are currently being investigated.[2,39] Becoming familiar with current guidelines can help clinicians make optimal treatment decisions for their patients in the present while also paving the way for integration of these future advances.

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RNS Chapters

JOIN A CHAPTER

The Rheumatology Nurses Society (RNS) is a professional organization that is committed to the development and education of nurses and other healthcare professionals to benefit its members, patients, family, and community. One of the valuable benefits of joining a Rheumatology Nurses Society (RNS) Chapter is the opportunity to engage with other healthcare professionals in your area, gain access to unique educational activities, and evidence-based accredited resources.

LEAD A CHAPTER

The RNS is rapidly expanding through the growth of local chapters and welcomes enthusiastic, driven, individuals who are eager to impact their communities. The RNS is looking for leaders to start a chapter in your area. We will equip you with the tools necessary to support the growth of your chapter. If you are a self-starter who is passionate about rheumatology and the vision of engaging with other rheumatology professionals in your city, contact the Chapter Development Team to get started today!

Join or lead *a chapter today. Contact the Chapter Development Team at* ***chapters@rnsnurse.org*** *or visit*

RNSnurse.org/Chapters

Picking Up Life Lessons from Our Patients

by Linda Grinnell-Merrick, NP-BC

Over the course of our careers, nurses, nurse practitioners, and other healthcare providers come into contact with hundreds and perhaps thousands of patients. While a big part of our job is providing medical-related education to these patients, we often learn just as much about life from them. Many of our interactions teach us about courage and bravery and stamina, leaving us with fond memories to look back on.

I have many such interactions stored in my memory bank. PR is one of my most cherished. She's a young woman who never fails to amaze me with her zest for life.

Let me share part of her story with you.

We'll start in mid-2016, approximately 1 month prior to her wedding. PR was 26 years old at the time and came into our office as usual accompanied by her mother, who had been her main support throughout her decade-long battle with rheumatoid arthritis (RA). PR was in the throes of a terrible disease flare, and an especially poorly timed one with her upcoming nuptials.

PR was being treated with rituximab at the time and was due for her next infusion in a few days, but she asked me if I thought it could wait until after her wedding and honeymoon. She was afraid that she might have an adverse reaction to the infusion that would interfere with her plans. PR put on a brave face. She was willing to accept the consequences of her disease flare so that she didn't ruin her wedding day not only for herself but for her future husband, his parents, and all of the other friends and family who were coming to celebrate.

Instead of her rituximab infusion, PR asked for a short court of steroids. It took a lot of pleading from PR's mom, her attending rheumatologist, and myself to convince her that this wasn't a good idea and that she was going to be much better off going through with the infusion so she could fully enjoy this special time in her life. We assured her that we would vigilantly monitor for any potential adverse effects to the medication.

This wasn't the first time I had had some really tough conversations with PR. We first met when she was 18 years old. She came into our clinic with pain and swelling in multiple joints. Lab tests revealed positive anti-nuclear antibodies, anti-citric citrullinated proteins (anti-CCP) levels, and rheumatoid factor (RF). We know that patients with both a positive RF and anti-CCP typically have a more aggressive course of RA and can be difficult to treat, so unfortunately PR had two strikes working against her right from the start.[1]

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“Nevertheless, PR never complained and accepted that her disease was a part of her life. Importantly, her disease never became her life, and she always came into our office with a smile.”

We started PR on a course of NSAIDs, prednisone, and hydroxychloroquine. We discussed the possibility of including methotrexate, but since PR was heading off to college in a few months, there was concern about possible drinking. An unplanned pregnancy was also a concern. Fortunately, instead of having to gently bring these issues up myself, PR’s mother did it for me. She had done a lot of reading to educate herself about treatments for RA and knew the risks of methotrexate before the topic ever came up.

Over the years, I saw PR on a semi-regular basis. There was a brief period where she and her mother sought out a second opinion from another local rheumatologist during one of PR’s disease flares, but they came back to our practice a few months later. We have often had to make adjustments to PR’s treatment regimen due to ongoing disease. Of course, as a young woman, life didn’t stop for PR, as she attended college full time while working 10-15 hours a week at a local grocery store. Nevertheless, PR never complained and accepted that her disease was a part of her life. Importantly, her disease never became her life, and she always came into our office with a smile. Because of her pleasant nature, we eventually created a strong bond not only as patient and provider, but as friends. We often share stories about our families and important milestones in our life.

It’s been a hard slog for PR. She’s been through the gamut of RA medications, ranging from infliximab to abatacept to tofacitinib. She developed rheumatoid nodules, which would be a horrifying development for many young women. Not for PR. She took it in stride.

After much trial and error, we finally hit upon a successful regimen approximately 4 years ago centered around rituximab that finally got PR’s disease under control. She was been able to finish college, accept a corporate-level job at the grocery chain she worked at during college, and had a beautiful wedding.

Her latest challenge involved planning for her first pregnancy. It was an exciting time and another important milestone in PR’s life, but always a situation that we as providers have to manage carefully. I worked with PR to time her final rituximab infusion prior to her trying to conceive and then transitioned her to hydroxychloroquine and prednisone.

Six months later, it was another good news/bad news scenario. PR was pregnant (good news!) but was again in an RA flare (bad news!). She came in and told me she was unable to dress herself or comb her own hair in the morning. It turns out that her Ob/Gyn had taken her off of prednisone due to a fear of cleft palate that is sometimes, but quite rarely, associated with steroid use during pregnancy.[2]

Based on her level of pain and inflammation, we referred PR to a high-risk Ob/Gyn as there was little chance she would be able to deliver a healthy baby in her current condition. Fortunately, her new

provider agreed to let PR resume use of low-dose prednisone, her joint symptoms resolved, and she delivered a healthy baby girl.

Alas, there was more bad news on the horizon. Two years following the birth of her daughter, PR was diagnosed with cervical cancer, requiring a total hysterectomy. This would have devastated some people, but as with everything else she's been through, PR sees this as just one more of life's challenges. Her optimism never seeks to amaze me. Instead of a "woe is me" attitude, she always says, "Look at all that I'm lucky to have. My family and my healthcare team do all they can to support me."

In the healthcare world, we too often look for those unusual cases, those rare diagnoses or treatment regimens that we feel the need to write about or present at conference. And yet it is patients like PR who take up most of our time. These are the real-life stories of perseverance and overcoming obstacles that inspire us to keep going and keep learning.

During the Covid-19 pandemic, we've heard a lot about the extra layer of challenges our families and patients are facing. I've been inspired over and over with the stories and love and perseverance I'm hearing from my patients during these difficult and challenging times. Our patients are far more than their diseases, and it's important for us to never forget about the person behind the diagnosis. Not only can we help them live a better life, but they can do the same for us.

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What Can We Do About Health Disparities in Rheumatology?

by Laura P. Kimble, PhD, RN, FNP-C, CNE, FAHA, FAAN

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In recent months, we have seen how society has shone a spotlight on racial injustices throughout the United States. For those of us who work in healthcare settings, we've likely seen the imbalance in care among specific racial and ethnic demographics play out time and time again. These health disparities have a profound impact both on the quality and quantity of care that patients receive, with proven impact on patient outcomes.

In a 2016 paper, Adler and colleagues defined health disparities as "differences in health that are avoidable and unjust."[1] In rheumatology, there are substantial racial and ethnic health disparities in the burden of disease as well as overall morbidity and mortality, with patients of color consistently having worse health outcomes. For example, one 2019 study showed that Black patients with systemic lupus erythematosus (SLE) were more likely to have more severe disease, as well as higher rates of mortality, compared to White patients. They were also found to die at a younger average age.[2] In a 2011 study of patients with rheumatoid arthritis, Black and Hispanic-Latino patients were both found to have greater disease activity and lower function compared to White patients.[3] Other studies have shown that Black patients are underrepresented in clinical trials, have more comorbidities, and lack easy access to subspecialty care.[4] Clearly then, while advances in treatments for rheumatic diseases have lengthened the lifespan of many of our patients, racial- and ethnicity-based health disparities persist.[5,6]

There are numerous drivers of health disparities in the United States. These include socioeconomic factors such as lower education and income, which negatively affect healthcare access and quality. Poor health outcomes are also related to chronic stress in persons of color who often have limited resources when faced with unexpected life events such as job loss or major illness.[1] Structural systems and policies that promote health inequities, which may not be self-evident to clinicians who are not racial or ethnic minorities, also are thought to play a role.[5] It's not as simple as a "Fix this one thing and everything will be OK" situation. There are numerous layers of issues that need to be explored with patients and carefully addressed.

Undoubtedly, the recent burden of the COVID-19 pandemic on communities of color has major implications for our approach to patient care. A recent article in *Arthritis & Rheumatology* shined a light on the pandemic's crushing impact and urged providers and researchers within rheumatology to take action to address widening health disparities.[4] A major takeaway from this article was that we must have a broad net for capturing sociodemographic data from patients so we can understand the complex situations that underlie health disparities.

Unlike many other specialties that see patients come and go as emergent health conditions arise and clear, rheumatology practices often establish long-term relationships with their patients due to the chronic nature of their

"We must proactively direct patients toward community resources and other networks to support those who need assistance."

disease. We know how to have hard conversations with our patients. Studies have shown that Black and Hispanic patients, along with patients with lower levels of education, are less likely than other groups to have advanced directives in place in case of unforeseen circumstances.[7] This can be one area where providers can make an immediate and profound impact amidst the COVID-19 pandemic.[4]

One of my most memorable patient encounters as a researcher was with a young, Black SLE patient who had been lost to follow-up for several years and then suddenly appeared back in our clinic with severe disease progression. Her life circumstances were such that she could not afford critical medications and was now at risk for renal failure. To see a young woman in her 20s facing a possible kidney transplant, especially knowing how preventable her complications could have been, was both sobering and sad. Patients who live in unstable conditions related to food or housing insecurity, lack reliable Internet access for telehealth visits, or are unable to pay for healthcare services due to unemployment need clinicians who can engage in discussions about how these conditions may be impacting their health. We must proactively direct patients toward community resources and other networks to support those who need assistance.[4]

One nurse I know who works primarily with medically underserved populations told me that her role is to be "the door" to help patients find the help they need. I liked that. Our patients shouldn't have to find the hidden key to access quality care. We all need to do a better job showing them how to unlock opportunities to overcome the many health disparity barriers in their way. By increasing our awareness of the core issues at play, we can be agents of change in promoting health equity for our patients of color.

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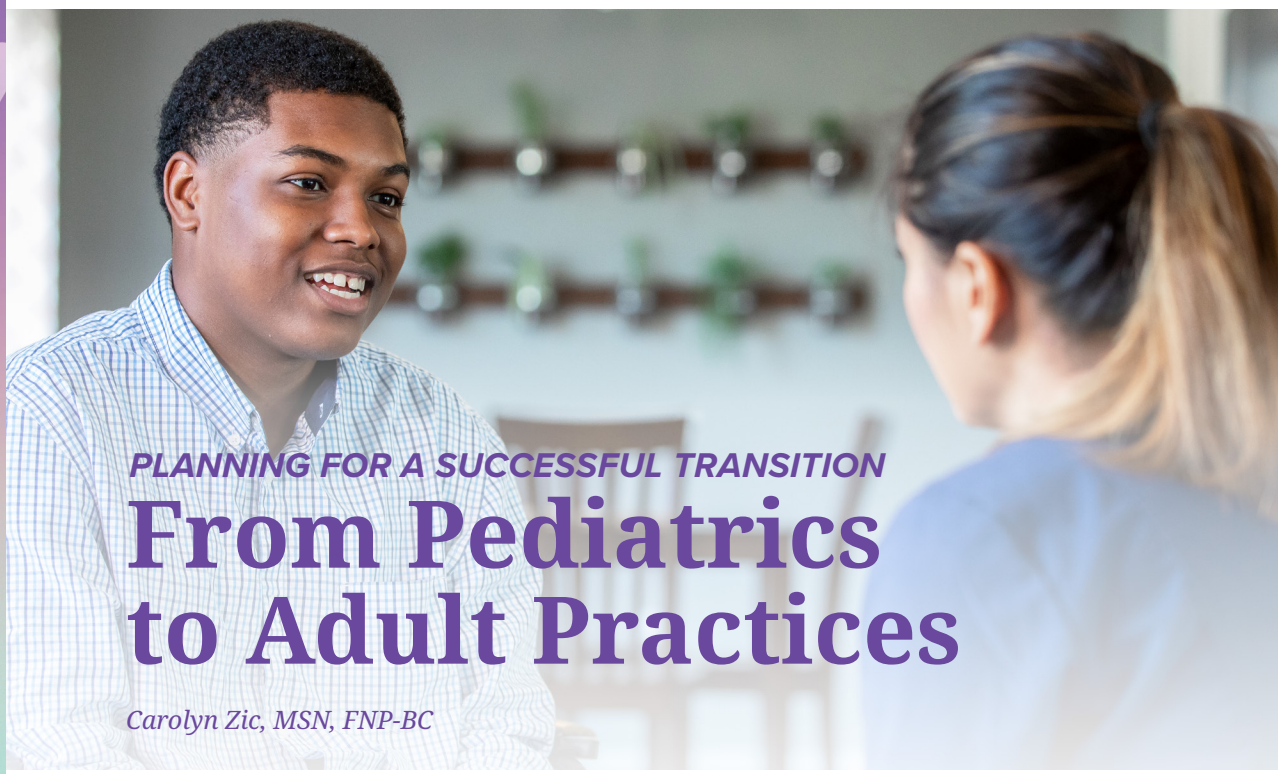

PLANNING FOR A SUCCESSFUL TRANSITION

From Pediatrics to Adult Practices

Carolyn Zic, MSN, FNP-BC

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It was Monday morning. I was feeling optimistic about the coming week. Of course, there would be some unforeseen challenges—there always are—but nothing that I wasn't feeling ready for.

But then I opened up my inbox and was immediately disheartened. There was a message sent on Sunday night about JC, an 18-year-old patient of mine who had just left home for his first year of college and was suffering what sounded like a pretty significant juvenile idiopathic arthritis (JIA) flare of multiple joints. This came as a bit of a surprise as his disease was under good control at his last visit. Adding to my dismay was that the information about this flare wasn't coming from JC but instead from his mom. She was worried. And so was I.

JC had been our patient for approximately 14 years. He was accompanied by one or both of his parents at every visit, and decisions about his care were typically made collaboratively amongst all of us. But as JC's freshman year of college approached, it was time for that dynamic to change. We spent what we thought was a considerable amount of time talking to JC about the importance of having him take the lead in his care. While JC didn't seem eager to take this on this responsibility, he agreed to do so. It wasn't that we wanted to cut out his parents entirely from helping to manage his JIA, we just wanted to help JC take ownership of his care, shifting the responsibility.

At his final in-person visit, we discussed how JC could reach our office with any questions and concerns he was having. It seemed like everything was in place. But on this Monday morning, reading this message about JC's struggles with his disease, it was clear that JC's mom was having a hard time letting go, and JC was struggling to take over his new responsibility. It was, of course, understandable. Mom was worried about her son and his disease, and also worried that JC wasn't going to reach out to us on his own.

It is unquestionably difficult to be a young adult, especially when you are starting your college education/career with the additional stress of a chronic condition. It's also difficult to be a parent, worried about when and if there will be a flare and how your child will handle it. I felt as if I had let both JC and his mother down by not preparing them as well as I should have.

For many, this may sound like a familiar scenario. As a patient, a parent, and/or a healthcare provider, we have likely all experienced some of the successes but also

"In pediatric rheumatology, we spend a lot of time seeing our patients grow and mature. It can be hard to transition our patients to adult practices, for both the family and ourselves."

faced some of the challenges that often accompany the transition from pediatric to adult healthcare, from "Ask mom and dad" to "It's up to me."

Adolescents and young adults are a unique and challenging cohort of patients to deal with. Preparing them to be responsible for their own healthcare and take charge of managing their disease is challenging. These are a number of barriers that have been identified that can impact the successful healthcare transition from adolescence to young adulthood, including the following:[1]

- Access to providers and health insurance
- Beliefs and expectations of the patient, parents, and provider
- Family relationships and dynamics
- Lack of knowledge of the patient about their condition
- Lack of knowledge of the adult provider on ways to work with adolescents and young adults

Aside from making everyone's life more pleasant, why is the transition of healthcare responsibilities so important? For starters, a majority of adolescents and young adult patients have clinically active disease at the time of transition.[1] In one study, 80% of 17-year-olds with JIA had clinically active disease, putting them at risk of poor disease outcomes.[2]

So then how can we successfully avoid situations like JC's where we think we've done everything right only to see it all unravel? It's not easy. The transition from pediatric to adult care needs to be carefully and purposefully planned out prior to implementation.[3] Unfortunately, many young adults have little guidance to help show them how to assume responsibility for their own care.[1]

There are some published standards we can lead on. The National Alliance to Advance Adolescent Health has identified six core elements of a successful healthcare transition. Providers can use these core elements to set up their own plan to assist with the successful transition of their pediatric patients to adult care.[4]

1. Have a transition policy
This might be a starting point or, in some instances, a sticking point. But by having a policy in place, you can educate both families and healthcare professionals about the transition process and set expectations.

2. Have a process for monitoring progress
It's important to be able to track a patient's progress and identify areas for improvement both for the patient and the healthcare team.

3. Start earlier rather than later
The National Alliance to Advance Adolescent Health recommends starting transition readiness at age 14. While this may seem young to many parents, it can help set the foundation to build upon throughout the years, creating a transition process and not a transition event.

4. Plan, plan, plan
Children and young adults who begin their care with pediatric providers typically have treatment decisions made and managed by their parents. Once patients turn 18 years of age, they are legally responsible for their own decisions. However, because it's a new role for them, the transition frequently creates unnecessary stress and communication breaks down in frustration.

Developing a comprehensive, thoughtful plan with both the patient and parent that includes specific milestones can help prepare all parties.

5. Follow through on the transition of care
It's like riding a bike—your patient may need a little push at the beginning, but they will hopefully soon get the hang of it. Make a referral to an adult rheumatologist and help the patient with scheduling the first appointment, making sure they have the number in the event they need to reschedule. It's also important to make sure the new provider has all of the records and history they need, including a transition summary. This can include important information such as current and past medications, uveitis history, positive serologies, and organ involvement.

6. Celebrate a successful transfer
This is a great time for ongoing collaboration between pediatric and adult providers to offer each other ongoing support. Remember that you are transitioning the patient to a new practice, not dumping them and washing your hands of any responsibility. Adult providers need to work hard to ensure that they integrate the young adult into their practice, and they may need some ongoing help. You are the one that knows your patient the best.

In pediatric rheumatology, we spend a lot of time seeing our patients grow and mature. It can be hard to transition our patients to adult practices, for both the family and ourselves. Nonetheless, it is incumbent upon us to do the best we can to prepare all of our young adult patients for a successful transition and emergence into the world of independent, adult health decisions. These are patients who can easily fall through the cracks and be lost to high-quality care until there is an emergent situation. That isn't good for anyone—not for the patient, not for the parents, and not for the provider.

By creating a solid plan that everyone agrees upon, we can give our maturing patients the best chance at success. It not our goal to leave parents out. We work together as a team, setting up the best possible course for the patient. It is important for us to remember that each family and situation is unique. For JC, it took some extra time to help both him and his mom through care transition. Looking back, if we had started sooner, setting up clear expectations and reiterating them throughout his ongoing care, the transition process may have been easier for everyone involved.

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What Rheumatology Patients Are Facing in the COVID-19 Era

by Mariah Zebrowski Leach

As someone who relies on several immunosuppressant medications to function, the onset of the COVID-19 pandemic was very, very scary for me. While the news kept trying to reassure people by emphasizing that the virus primarily impacts those who are elderly or have pre-existing conditions, even my 7-year-old was smart enough to see the flaw in that logic.

"What about you, mama?" he asked me.

I talked to him honestly about my risk as a woman diagnosed with rheumatoid arthritis (RA) and calmly emphasized that staying isolated at home would keep our family safe and make the world safer for everyone else, too. Yet while I've maintained an optimistic outlook for my kids, internally I've been struggling with anxiety.

As lockdown orders and other precautions lifted, I expected my anxiety to lift too—but the opposite has occurred. I watched in horror as people "went back to normal" even as infection numbers continued to increase. At the same time, I felt guilty for keeping my kids isolated when they could see the neighborhood kids playing together again through our front window. And as fall approached, I struggled with the fact that my higher risk may necessitate my kids returning to a less-than-ideal learning situation online, even as their friends return to school in person.

That said, I knew I couldn't be the only patient living with a rheumatic disease who was struggling to see a path forward. And so, I reached out to a few friends to hear about their experiences during the COVID-19 pandemic. Here is what they told me.

(Note: Some names have been changed to protect patient privacy)

Rick's Story

Some patients with rheumatic diseases had no choice but to continue entering hospitals during the pandemic to receive the care they need. This was the case for Rick, who has been living with type 1 diabetes for 46 years, RA for 21 years, and ankylosing spondylitis (AS) for 5 years.

In early March, Rick had to have a necessary and extensive surgery to repair his back. His difficult and ongoing recovery, which included regular physical therapy, all took place during the pandemic. When I asked Rick how he felt about the COVID-19 risk, he told me, "I would say I am scared to death, and I seldom get afraid. I know that society is discounting my situation."

Despite his fear, Rick said he was very impressed with the quality of the medical team responsible for his care post-surgery. He said his rheumatology nurses went out of their way to keep his infusions on schedule, have prescription refills delivered to his house, and take care of him in the infusion center. "Sometimes it takes a village to run a rheumatology patient," Rick said. "These past few months it has taken a huge village, indeed."

AUTHOR BIO

Mariah Zebrowski Leach

Mariah Zebrowski Leach is a writer, patient advocate, and mom of three living with rheumatoid arthritis. After learning firsthand the challenges of facing pregnancy and motherhood with a chronic illness, Mariah became passionate about supporting women with chronic illnesses who are or want to become mothers. She launched ***Mamas Facing Forward*** *in 2015.*

Jed's Story

For less urgent medical needs, patients living with rheumatic diseases have needed to weigh a variety of factors, including between the risk of exposure, the value of telehealth appointments, and simply delaying medical care. Jed, who has been living with AS for 26 years, runs a Facebook group that supports more than 27,000 patients. Within that group, he has seen a lot of debate about the value of telehealth appointments.

"Some people really appreciated the ability to have an appointment without leaving the house," Jed explained, "but many felt they were getting ripped off because there was no physical examination, yet they were paying the same co-pay."

Personally, Jed chose to delay bloodwork for more than 6 months because he didn't want to go to the hospital lab and potentially be exposed.

"I avoided taking medications that need to be monitored, like NSAIDs, because in the past they have affected my liver and kidneys," he said. "Without proper monitoring, it could cause trouble."

Unfortunately, foregoing the medications has caused trouble too—Jed began experiencing more stiffness and pain in his peripheral joints. As the pandemic stretches on, it's unclear how much longer it will be reasonable to delay his care.

Lene's Story

For patients with physical disabilities and mobility issues, the pandemic has often made assistance inaccessible. Lene has lived with RA since she was 4 years old. Due to RA-related deformities in her hands, she is unable to self-inject her biologic medication. Prior to the pandemic, Lene's family doctor did the injections, but with reduced clinic hours and fear of exposure, that no longer became an option. Luckily, Lene found a solution by combining households with her partner so he could administer injections, but she knows not all patients are lucky enough to have that level of help.

"I'm thankful I didn't have to make the choice between putting myself at risk or going without my biologic," Lene said. "I worry about others in the RA community whose conditions are not under control or who need to enter clinics for appointments and infusions."

Lene also emphasized the psychological burden on high-risk patients, especially those who have experienced past medical trauma. Four years ago, Lene ended up in the intensive care unit due to influenza-related complications and was on a ventilator for 2 weeks. The recovery, both physically and emotionally, was intense. Diagnosed with medical PTSD, Lene has been constantly triggered by news about the pandemic and the behavior of other people.

"A lot of people don't seem to worry about their own risk or the risk they pose to others," she said. "That's been really hard for me, on top of all the other difficult things about living in these times."

How Healthcare Providers Can Help

Personally, I've chosen a combination of telehealth visits and outright delay for my own medical care during the pandemic. I had one telephone consultation with my rheumatologist, where he gave me a general idea of my level of risk. He also advised me to stay home and delay the bloodwork I should have had in March.

Since then, I haven't been anywhere or interacted with anyone outside of my own home and family. I've been lucky that my biologic has been delivered without delays, and my husband has been able to pick up the rest of my prescriptions when he does our grocery shopping.

Recently, however, I've experienced some concerning symptoms. I emailed my rheumatologist, and he's now asked me to complete my delayed bloodwork. I'm trying to work up the courage to do so. With my diagnosis, I know I can't delay medical care indefinitely—and I suspect many other patients in my situation are starting to come to the same conclusion.

In this unprecedented situation, I hope that healthcare providers remember the intense psychological toll the COVID-19 pandemic continues to have on patients who are already managing the emotional impact of living with lifelong rheumatic diseases. Patients utilizing telehealth services need to feel that the time and money they invest is worthwhile, and patients who require in-person attention need reassurance that the care they need can be delivered safely.

To get through this pandemic physically and psychologically, patients living with rheumatic diseases need compassionate providers who can look at the whole picture and provide as much support as possible.

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