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

WHERE DO WE BEGIN? EXPLORING OPTIONS IN NEWLY-DIAGNOSED PATIENTS WITH RA

Inside this Issue

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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

In this issue of *Rheumatology Nurse Practice*, we will look at the key components of the first several visits to a rheumatology practice for an individual with suspected or newly diagnosed rheumatoid arthritis (RA), including the diagnostic and disease classification process as well as initial approaches to treatment for patients naïve to disease-modifying anti-rheumatic drugs.

LEARNING OBJECTIVES

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

- Explain the key components of the initial visit of a patient with suspected RA to the rheumatology clinic
- Develop a checklist of questions to ask patients with suspected RA at the initial and subsequent visits to the rheumatology clinic
- Discuss the importance of validated disease measurement tools in patients with RA
- Identify the components of the American College of Rheumatology/European League Against Rheumatism classification criteria for RA

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WHERE DO WE BEGIN? EXPLORING OPTIONS IN NEWLY-DIAGNOSED PATIENTS WITH RA

Rheumatoid arthritis (RA) is a chronic, systemic, autoimmune disease typified by inflammatory polyarthritis of the peripheral joints, particularly the small joints of hands and feet.[1-4] It is believed to affect 1–2% of the population globally, including an estimated 1.28 to 1.36 million adults in the United States.[5,6] RA is considered a progressive disease. In addition to joint destruction, pain, and functional impairment, patients with RA may experience reduced quality of life and are at risk of developing a variety of other medical conditions.[3,4,7]

The presentation of RA varies widely from patient to patient. Symptom onset may be gradual, acute, progressive, or intermittent with periodic symptom flares.[8] Many individuals diagnosed with RA may experience pain, swelling, morning stiffness >30 minutes, or warmth in one or more joints, as well as a variety of other symptoms such as fatigue, weight loss, low-grade fevers, weakness, dry eyes and mouth, or entrapment neuropathy (e.g., carpal tunnel). Joint involvement is typically symmetric.[2,3] A number of other conditions must be considered in patients presenting with joint pain and swelling, such as systemic lupus erythematosus (SLE), psoriatic arthritis (PsA), gout, osteoarthritis, connective tissue disease, and post-viral arthritis.[1,2,8,9]

ACCREDITATION AND CREDIT DESIGNATION

Nurses

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Rheumatology Nurses Society designates this educational activity for 3.4 contact hours (1.0 pharmacotherapeutic contact hours).

METHOD OF PARTICIPATION

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Drug Names Included Within This Issue

GENERIC	BRAND
Leflunomide	Arava
Hydroxychloroquine	Plaquenil
Naproxen	Aleve, Naprosyn, and others
Liraglutide	Victoza, Saxenda
Ezetimibe	Zetia
Losartan	Cozaar
Conjugated estrogen	Premarin
Carvedilol	Coreg
Adalimumab	Humira
Infliximab	Remicade
Golimumab	Simponi

It has been unequivocally established that early diagnosis, coupled with early and aggressive use of disease-modifying anti-rheumatic drugs (DMARDs), is associated with less joint damage and improved physical functioning compared with delayed start of DMARD therapy in patients with RA.[2,10–12] Best practices indicate patients presenting with signs and symptoms suggestive of inflammatory arthritis (e.g., persistent synovitis of undetermined cause) should receive an urgent referral to rheumatology and be evaluated by a rheumatologist within 6 weeks of symptom onset.[4,13–16] The presence of normal inflammatory markers or imaging, along with negative serology, should not delay initiation of referrals, as these are often normal in the early phase of disease.[4,9,15,16] Data indicate patients referred to a rheumatology practice early (within 3 months of symptom onset) have better clinical outcomes, including reduced joint damage, and better chance of achieving DMARD-free remission.[17,18]

The First Visit

Providing optimal care to patients with RA requires the participation of a multidisciplinary team, with the rheumatology nurse being a key player. RA is primarily a clinical diagnosis based upon careful history and physical exam, with laboratory and radiographic evaluations helping to confirm the diagnosis.[4] A new patient's first visit to a rheumatology clinic is typically focused on the following components:

- Gathering information and establishing baselines
- History and physical exam
- Ordering laboratory tests and imaging as indicated
- Initiating therapies for symptomatic relief as needed
- Cultivating a therapeutic relationship with patients and caregivers
- Beginning to provide education and support to individuals and caregivers

The end goal of this first visit is to establish a relationship to ensure patient-centered care that involves the physical, social, and emotional well-being of RA patients.

Data on the type and frequency of evaluations that occur in the primary care setting for possible RA prior to referral to a rheumatology clinic is scarce. However, one study found 24% of referrals for joint pain from the primary care setting did not contain any information (e.g., joint count, seropositive disease, inflammatory markers, or duration of symptoms) relevant to reaching a diagnosis of RA.[19]

As such, some patients may arrive with little information and evaluation beyond a complaint of joint pain while others may arrive with a presumptive or definitive diagnosis of RA; therefore, the labs and imaging tests ordered during the initial visit as well as initial treatment plans will vary from patient to patient.

Patient History

Establishing the chief complaint and eliciting a thorough patient history about symptoms, duration of symptoms, previous evaluations and treatment, family history, and relevant medical history are key components of the initial visit to establish a rapport, develop a working diagnosis, and devise possible approaches to disease management. Table 1 presents a sampling of questions that nurses may want to ask new patients at the first visit.

In order to determine what initial laboratory or imaging tests may be appropriate, it is important to obtain past medical records related to the chief complaint when available. In addition to medical records and new patient information sheets, patient-administered outcome measures completed at or before the first visit can be an integral component of establishing baseline disease activity and disability. Examples of three commonly used validated composite tools to assess the impact of RA on daily life include the following:

- Patient Activity Scale (PAS), which includes a Health Assessment Questionnaire (HAQ), Pain Visual Analog Scale (VAS), and Patient Global VAS

Table 1

EXAMPLES OF QUESTIONS TO ASK RA PATIENTS AT THE FIRST VISIT

Why are you here today?

What do you think is going on?

What are you worried about?

How long have you had symptoms?

What time of day do you find that your symptoms are worst?

Is this the first time you have had symptoms like this or do your symptoms come and go?

Have you noticed any swelling or tenderness in your joints?

Can you show me which joints have been bothering you?

Have you noticed any other symptoms (skin changes, fatigue, fevers, weight loss, etc.)?

Have you found anything that seems to make your symptoms better or worse?

Are there any activities that you have noticed are more difficult to do than normal (e.g. opening jars, tying shoelaces, getting in and out of bed)?

What have you tried so far to treat your symptoms (e.g. NSAIDs, herbal, non-pharmaceutical)

Have you undergone any type of evaluation for your symptoms (labs, x-rays)?

Do you have a personal and/or family history of rheumatoid arthritis, lupus, or another autoimmune disease?

Do you have any other health issues that you know of?

What current medications, including over-the-counter drugs and supplements/ vitamins, are you taking?

How do you feel about taking infusible or injectable drugs to help control your pain?

(For females of child-bearing age) Are you taking birth control?

Are there any important life events coming up for you in the next few weeks or months?

What are your treatment goals, and how would you like to achieve them?

What questions do you have for me?

- Patient Activity Scale-II (PAS-II), which includes a HAQ-II; Pain VAS, and Patient Global VAS
- Routine Assessment of Patient Index Data with 3 Measures (RAPID 3), which includes a Multidimensional HAQ (MDHAQ), Pain VAS, and Patient Global VAS. A sample of a completed RAPID-3 questionnaire is included in Figure 1.

These assessments can easily be completed at point-of-care and used to monitor patient functional status, disease activity, and response to treatment. Each of the composite tools (PAS, PAS-II, and RAPID-3) produce a single score on a continuous scale (0-10), with set thresholds for remission and disease activity cut-offs.[20]

Disease activity measures such as the HAQ, HAQ-II, and MDHAQ assess the impact of disease on current activities of daily living as well as pain, fatigue, sleep, and morning stiffness over the last week. The MDHAQ additionally assesses the impact of disease on a patient's global status. On these forms, the patient checks a box that best describes their current state; points are then assigned and tallied, ranging from "without any impact" (0 points) to "major impact" (higher point values). The higher the score, the greater the disease activity and disability.

In contrast, the Pain VAS and Patient Global VAS both utilize a horizontal line (ranging from 0 to 10), anchored respectively by "no pain" and "pain as bad as it could be" and "very well" and "very poorly." Patients select one point on the line that best represents their current level of pain and the effect of RA on their global status during the past week. A single numerical score is assigned. Once again, higher scores indicate worse pain and global status.[21]

Physical Exam

Physical findings are key to supporting a diagnosis of RA. Joint counts that determine the number of tender and/ or swollen joints involve a straightforward assessment and widely accepted measure of disease activity (see pull-out poster for more details on joints commonly assessed during physical exam). RA tends to affect and spare specific joints.[8]

On physical exam, joint synovitis findings can include warmth, soft tissue swelling, pain and a "boggy, squishy, or doughy" feeling upon palpation, in contrast to bony enlargement or synovial fluid felt with osteoarthritis.[4,8] Skin creases over the proximal interphalangeal joints may become less apparent due to swelling, grip strength may be reduced, and thickening of nodularity of the tendons may be felt.[8,22] Squeezing the metacarpophalangeal or

Figure 1

ROUTINE ASSESSMENT OF PATIENT INDEX DATA

The RAPID3 includes a subset of core variables found in the Multi-dimensional HAQ (MD-HAQ). Page 1 of the MD-HAQ, shown here, includes an assessment of physical function (section 1), a patient global assessment (PGA) for pain (section 2), and a PGA for global health (section 3). RAPID3 scores are quickly tallied by adding subsets of the MD-HAQ as follows:

1. Please check the *ONE* best answer for your abilities at this time:

OVER THE LAST WEEK, were you able to	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do
a. Dress yourself, including tying shoelaces and doing buttons?	0	X 1	2	3
b. Get in and out of bed?	0	X 1	2	3
c. Lift a full cup or glass to your mouth?	0	1	2	X 3
d. Walk outdoors on flat ground?	X 0	1	2	3
e. Wash and dry your entire body?	X 0	1	2	3
f. Bend down to pick up clothing from the floor?	0	X 1	2	3
g. Turn regular faucets on and off?	0	1	X 2	3
h. Get in and out of a car, bus, train, or airplane?	0	1	X 2	3
i. Walk two miles or three kilometers, if you wish?	0	X 1	2	3
j. Participate in recreational activities and sports as you would like, if you wish?	X 0	1	2	3
k. Get a good night's sleep?	0	1.1	2.2	3.3
l. Deal with feelings of anxiety or being nervous?	0	1.1	2.2	X 3.3
m. Deal with feelings of depression or feeling blue?	0	1.1	X 2.2	3.3

1. a-j FN (0-10): 3.7

1=0.3 16=5.3
2=0.7 17=5.7
3=1.0 18=6.0
4=1.3 19=6.3
5=1.7 20=6.7
6=2.0 21=7.0
7=2.3 22=7.3
8=2.7 23=7.7
9=3.0 24=8.0
10=3.3 25=8.3
11=3.7 26=8.7
12=4.0 27=9.0
13=4.3 28=9.3
14=4.7 29=9.7
15=5.0 30=10

2. PN (0-10): 2.5

3. PTGE (0-10): 1.0

RAPID3 (0-30) 7.2

2. How much pain have you had because of your condition *OVER THE PAST WEEK?*

Please indicate below how severe your pain has been:

NO PAIN — *PAIN AS BAD AS IT COULD BE*

○ 0 ○ 0.5 ○ 1.0 ○ 1.5 ○ 2.0 ● 2.5 ○ 3.0 ○ 3.5 ○ 4.0 ○ 4.5 ○ 5.0 ○ 5.5 ○ 6.0 ○ 6.5 ○ 7.0 ○ 7.5 ○ 8.0 ○ 8.5 ○ 9.0 ○ 9.5 ○ 10

3. Considering all the ways in which illness and health conditions may affect you at this time

Please indicate how well you are doing:

VERY WELL — *VERY POORLY*

○ 0 ○ 0.5 ● 1.0 ○ 1.5 ○ 2.0 ○ 2.5 ○ 3.0 ○ 3.5 ○ 4.0 ○ 4.5 ○ 5.0 ○ 5.5 ○ 6.0 ○ 6.5 ○ 7.0 ○ 7.5 ○ 8.0 ○ 8.5 ○ 9.0 ○ 9.5 ○ 10

CONVERSION TABLE

Near Remission (NR): 1=0.3; 2=0.7; 3=1.0
Low Severity (LS): 4=1.3; 5=1.7; 6=2.0
Moderate Severity (MS): 7=2.3; 8=2.7; 9=3.0; 10=3.3; 11=3.7; 12=4.0
High Severity (HS): 13=4.3; 14=4.7; 15=5.0; 16=5.3; 17=5.7; 18=6.0; 19=6.3; 20=6.7; 21=7.0; 22=7.3; 23=7.7; 24=8.0; 25=8.3; 26=8.7; 27=9.0; 28=9.3; 29=9.7; 30=10.0

HOW TO CALCULATE RAPID 3 SCORES

1. Ask the patient to complete questions 1, 2, and 3 while in the waiting room prior to his/her visit.
2. For question 1, add up the scores in questions A-J only (questions K-M have been found to be informative, but are not scored formally). Use the formula in the box on the right to calculate the formal score (0-10). For example, a patient whose answers total 19 would score a 6.3. Enter this score as an evaluation of the patient's functional status (FN).
3. For question 2, enter the raw score (0-10) in the box on the right as an evaluation of the patient's pain tolerance (PN).
4. For question 3, enter the raw score (0-10) in the box on the right as an evaluation of the patient's global estimate (PTGE).
5. Add the total score (0-30) from questions 1, 2, and 3 and enter them as the patient's RAPID 3 cumulative score. Use the final conversion table to simplify the patient's weighed RAPID 3 score. For example, a patient who scores 11 on the cumulative RAPID 3 scale would score a weighed 3.7. A patient who scores between 0–1.0 is defined as near remission (NR); 1.3–2.0 as low severity (LS); 2.3–4.0 as moderate severity (MS); and 4.3–10.0 as high severity (HS).

metatarsophalangeal joints may also elicit pain (positive MCP squeeze test).[4]

A typical initial physical exam should also include an assessment of range-of-motion.[8] Patients with long-standing disease may also present with rheumatoid nodules and characteristic hand deformities such as ulnar deviation, Boutonniere deformity, flail thumb, and Swan-neck deformities.[2] The skin should also be examined for any clinical findings (e.g., rashes, thickening) that may indicate other autoimmune disorders such as SLE, systemic sclerosis, and PsA.[22]

Initial Laboratory Evaluations

Several laboratory tests are important to collect at the initial visit to establish baseline values, assist in the diagnosis and prognostic evaluation of RA, guide treatment decisions, and monitor disease activity and response to therapy.[18] The laboratory tests commonly used in suspected RA include autoantibodies, acute phase reactants, and hematologic parameters.

Autoantibodies

Autoantibodies reflect the autoimmune disease process and are important tools for diagnostic and prognostic purposes in patients with RA.

Rheumatoid factor (RF) was the first autoantibody to be associated with RA and is found in approximately 80% of patients with the disease.[23,24] Importantly, RF is not specific for RA and may be present in patients with other diseases, such as hepatitis C, HIV, subacute bacterial endocarditis, sarcoidosis, SLE, or in healthy older people. While the sensitivity and specificity of RF in early disease is lower than in established disease,[2,24,25] a pooled analysis found the overall sensitivity of RF is 69% and the specificity is 85%.[26] In patients with RA, the presence of RF is associated with more severe disease, radiographic erosions, and extra-articular manifestations.[23,25,27]

In contrast, **anti-citrullinated protein antibodies (ACPAs)**, found in approximately 75% of patients with RA, are often present before a clinical diagnosis of RA is made.[23] The sensitivity of ACPAs are similar to RF, but are notably more specific, even in patients with early disease.[2,25,26,28] ACPAs are associated with aggressive erosive disease, with data suggesting that the risk for substantial ongoing disease activity and radiographic disease progression is increased with ACPA positivity compared with RF positivity.[23,26,29]

A patient is considered to have *seropositive disease* if they test positive for RF, ACPAs, or both. Seropositive RA is associated with more severe disease, greater extra-articular manifestations, and a worse overall prognosis. Approximately 15-26% of RA patients have *seronegative disease*, with both RF and ACPAs testing negative.[23,30] The levels of RF and ACPAs tend to remain stable or decline slightly throughout the course of disease, with few patients experiencing seroconversion from positive to negative status, or vice versa.[25,29] Therefore, RF and ACPA are useful for the diagnosis of RA; however, the clinical utility of repeat RF and ACPA testing to monitor disease activity is of little value.[24]

Antinuclear antibodies (ANAs) may be present in 20% to 30% of individuals with RA.[2] ANAs are frequently positive in patients with connective tissue disease. The sensitivity of ANA testing in patients with RA is ~40%, which is much lower than other conditions such as drug-induced lupus (~100%), SLE (~99%), scleroderma (~97%), and Sjogren's syndrome (~96%). Thus, the clinical utility of ANA testing in patients with suspected RA is of limited value.[24]

Acute Phase Reactants

While not specific to RA, the acute phase reactants, specifically **erythrocyte sedimentation rate (ESR)** and **C-reactive protein (CRP)**, may reflect the current state of the inflammatory process and tend to parallel RA disease activity and symptoms.[2,24] ESR is often elevated in patients with RA; however, there are many factors that interfere with ESR. Similarly, an elevated CRP can be due to non-RA related factors.[31] Patients with RA may present with discordant findings. In one study (N=478), ESR was normal at baseline in 47% of patients diagnosed with RA, CRP was normal in 58%, and both ESR and CRP were normal in 42%.[32] Similar results were reported in a recent analysis of patients (N=9,135) with active RA (Clinical Disease Activity Index score >2.8) in the Consortium of Rheumatology Researchers of North America (CORRONA) registry. In this study, 58% of patients had normal ESR or CRP, 26% had elevations in either ESR or CRP, and 16% had elevations in both ESR and CRP.[33] Both ESR and CRP may be used to assess disease activity and monitor response to therapy along with physical exam and clinical presentation.[2,24] Persistently elevated levels of acute phase reactants in patients with RA is associated with increased joint destruction and mortality.[2,23,34]

Other Laboratory Tests

It is also important to obtain a complete blood count and assess a patient's hepatic and renal function levels prior to initiating therapy as these will need to be regularly monitored in patients with RA receiving DMARDs and may influence choice of therapy.[2,22,35] Patients with RA frequently demonstrate hematologic abnormalities, such as anemia of chronic disease or thrombocytosis, both of which correlate with disease activity.[2,36,37] Synovial fluid analysis may also be obtained in select patients to assist in differential diagnosis.[2,34]

More recently, composite multi-biomarker disease activity panels have been developed that assist in the diagnosis of RA and can be used to evaluate disease activity, risk of joint damage, and response to therapy.[38] The use of these assessments may be particularly helpful for patients who have seronegative disease or have normal to mildly elevated acute phase reactants. Vectra Disease Activity (DA) is one such panel that measures 12 proteins representing multiple biologic pathways that drive RA disease activity and combines them into a single score. This score may provide a more complete measure of disease activity compared with CRP or ESR. VectraDA has been validated in clinical trials against the DAS28-CRP and DAS28-ESR scores in both seropositive and seronegative patients and has been found to significantly correlate with changes in disease activity.[39,40]

Imaging

X-rays of affected joints along with the hands, wrists, and feet are useful to obtain early in the diagnostic process to establish a baseline for future evaluations of disease progression. In addition, erosive damage typical of RA may be present even if other tests are normal.[4] Radiological findings of early RA include periarticular osteopenia, symmetrical joint space narrowing, and soft tissue swelling. More advanced RA findings due to cartilage and bone destruction secondary to pannus formation include periarticular erosions, marginal erosive changes, and deformities.[2]

Other imaging techniques such as ultrasound and MRI are more sensitive than x-ray for detecting bone edema, erosive disease, joint effusion/synovitis, and tenosynovitis. Ultrasound and MRI may be used to confirm the clinical examination and diagnosis, especially in the event that x-rays do not show damage; however, MRI is no longer recommended as part of a routine evaluation due to accessibility, patient comfort, and cost.[13,41]

In addition to establishing a baseline for monitoring disease progression, imaging provides prognostic information. Baseline presence of erosive changes, bone edema, joint effusion/synovitis, and tenosynovitis are associated with more aggressive disease and erosive progression.[22,41]

At the end of the initial visit following diagnosis of RA, patients should be provided with reassurance, introductory education, and resources about RA and its management, as well as immediate symptomatic relief (see **Put Your Rheumatology Specs Away with New Patients** essay later in this issue). Symptomatic relief that leads to decreased pain, improved sleep, and improved activities of daily living and social life is often a top priority for patients with suspected or definitive RA. A short course of glucocorticoids (GCs) may be appropriate for patients with a presumptive working diagnosis of new-onset RA who are GC-naïve, as GCs can provide rapid symptomatic relief as well as functional quality-of-life benefit.[4] In select patients, NSAIDs may also be considered for symptomatic pain relief; however, they should be used at the minimum effective dose for shortest time possible in order to avoid potential adverse effects.[13] A follow-up visit should be scheduled, typically within 10-14 days.

The Second Visit

Results of laboratory and imaging findings are typically available within a few weeks after being ordered. Consequently, the primary goals of the second visit for a patient with a suspected diagnosis of RA are as follows:

- Review laboratory and imaging results (if ordered)
- Repeat disease activity assessment
- Determine if any symptomatic interventions were/were not effective
- Discuss if a diagnosis of RA is supported
- Collaborate with patient to establish goals and expected outcomes for successful disease management, pharmaceutical and otherwise
- Initiate DMARD therapy in DMARD-naïve patients with newly diagnosed RA

The second visit is also an opportunity to assess patient and caregiver understanding of RA and potential short- and long-term management options, as well as provide ongoing reassurance, education, and support (see Table 2). Studies have shown that appropriate levels of patient education increases adherence to drug treatment.[42] However, like everyone, patients are susceptible to information overload. Given that RA is a chronic disease, it is important for providers to remember that there will be frequent opportunities to review information as well as provide additional details during the course of treatment.

Establishing a Diagnosis of RA

RA is a clinical diagnosis that is reached based upon careful history and physical exam, laboratory results, and/or imaging findings. There is no "gold standard" for determining a diagnosis of RA; therefore, strict RA diagnostic criteria have not been developed.[43] However, in 2010 the American College of Rheumatology/European League Against Rheumatism (ACR/EULAR) Collaborative Initiative developed new classification criteria for RA that were designed to enhance sensitivity for early disease detection. In contrast with the earlier criteria from 1987, the presence of symmetric arthritis, rheumatoid nodules, and radiographic changes were no longer included as classification criteria.[1,44] While originally developed to facilitate clinical trials of individuals with earlier stages of RA, the use of these criteria have been used to support the clinical diagnosis and management of patients newly presenting with RA in the clinical setting as well.[45]

The classification criteria are targeted for use in patients who must meet the following two eligibility criteria:

1. There must be clinically active synovitis (pain, swelling, tenderness) in at least one joint as determined by an expert assessor
2. The observed synovitis is not better explained by a better diagnosis.

Patients are assigned points for joint involvement (the size and number of tender and/or swollen joints; score range 0–5), laboratory findings (serology [negative/positive RF and/or ACPA]; score range 0–3), acute phase reactants [normal/abnormal ESR or CRP]; score range 0–1), and duration of symptoms (<6 weeks or ≥6 weeks; score range 0–1). Patients are classified as having definite RA if they receive a score of 6 or greater; patients with a score <6 are not classified as having RA, but their status can be reassessed over time. While the classification criteria are aimed at classification of newly presenting patients, patients with longstanding disease, including those with inactive disease, as well as patients with erosive disease typical of RA with histories compatible with fulfillment of 2010 criteria, should be classified as having RA. In contrast to the 1987 ACR/EULAR criteria, evidence of more advanced disease, such as the presence of erosions/decalcification on x-ray imaging or rheumatoid nodules, are no longer included.[1] Further details on these classification criteria are included in the pull-out poster included within this issue.

In the real-world setting, the ACR/EULAR classification criteria have proven useful for both classification and diagnostic purposes.[46] In one study, patients with symptoms of possible early arthritis ≤12 months duration were referred for consultation to the Rotterdam Early Arthritis Cohort (REACH) between 2004–2008. The ACR/EULAR 2010 classification criteria (cut-point ≥6 points) were used to identify patients in need of treatment. The criteria demonstrated good diagnostic ability, with patients either using methotrexate or having persistent disease at 1-year follow-up being classified as being correctly diagnosed.[47] A more recent study evaluated the 2010 and 1987 classification criteria in patients with joint symptoms ≤12 months duration who were DMARD-naïve. DMARD initiation within the first year following diagnosis was assessed as the primary outcome. The authors reported that the 2010 criteria had higher sensitivity, but lower specificity compared with the 1987 criteria (73.5% vs 47.1% and 71.4 vs 92.9%, respectively).[48] Thus, the 2010 criteria may be more useful for capturing patients with early RA compared to the 1987 criteria; however, the 2010 criteria are also more likely to misclassify patients as having RA when in fact they don't have the disease. A meta-analysis evaluating the performance of the 2010 criteria in the clinical setting supports these findings.[46]

Disease Severity and Disease Activity

Disease progression has been categorized into 4 distinct stages based upon radiographic evidence of joint changes and destruction secondary to chronic inflammation, including Stage 1 (early), Stage 2 (moderate), Stage 3 (severe), and Stage 4 (end-stage) These stages generally correspond to typical clinical signs and symptoms as well as other indicators of disease activity and changes in functional capacity.[7,49–55] Early use of DMARDs have been shown to slow the progression of RA and are associated

Table 2

Key Nursing Actions Over First Several Visits and Beyond *[4,35,56,57,71]*

- Establish therapeutic relationship
- Identify patient learning style and preference
- Assess patient and caregiver understanding of RA and its management
- Provide appropriate consumer health material
- Collaborate with patient to set short- and long-term goals
- Emphasize the importance of adherence to therapy to control pain and minimize future damage, both to joints and other systems
- Teach patients how to recognize medication side effects
- Evaluate patients' physical, emotional, and psychological well-being
- Discuss common RA-related psychological factors such as depression, anxiety, and stress and possible coping strategies (relaxation, stress management, cognitive coping skills)
- Discuss non-pharmacological approaches to disease management such as joint protection, heat and cold therapy, range-of-motion exercises, physical therapy, occupational therapy, assistive devices, and complementary and alternative therapies
- Promote self-care and the 4 Pillars of Wellness (exercise, diet, sleep, and mind/body)
- Reinforce the importance of a multidisciplinary team approach to care
- Initiate care coordination with PCP to address disease- and treatment-related comorbidities such as cardiovascular risk factors, osteoporosis prevention, fertility, and infection risk

with improved function and better radiological outcome.[9] However, both favorable and unfavorable patient factors may influence the risk of progression and outcomes. Factors associated with a poor prognosis in RA include the following:[13,23,56–58]

- High levels of acute phase reactant
- High number of swollen joints
- RF and/or ACPA positivity, especially at high levels and in duality
- Moderate to high disease activity after conventional DMARD therapy according to composite measures
- Functional limitation as measured by HAQ score or another similar validated tool
- Failure of two or more conventional DMARDs
- Radiographic evidence of early bony erosions at presentation
- Presence of nodules or other extra–articular features
- Female gender
- Past or current smoking
- Obesity
- The presence of the shared epitope
- Number of HLA and non–HLA alleles

Table 3 *Validated Composite Measures for Assessing Disease Activity*[10,22]

	Instrument	Score Range	Included Elements	Thresholds of disease activity
Patient-driven composite tool	Patient Activity Scale (PAS)	0-10	HAQ; Pain VAS; Patient Global VAS	**Remission:** 0-0.25 **Low activity:** >0.25-3.7 **Moderate activity:** 3.71 to <8.0 **High activity:** ≥8.0
	Patient Activity Scale-II (PAS-II)	0-10	HAQ-II; Pain VAS; Patient Global VAS	**Remission:** 0-0.25 **Low activity:** >0.25-3.7 **Moderate activity:** 3.71 to <8.0 **High activity:** ≥8.0
	Routine Assessment of Patient Index Data with 3 Measures (RAPID-3)	0-10	MDHAQ; Pain VAS; Patient Global VAS	**Remission:** 0-1.0 **Low activity:** >1.0 to 2.0 **Moderate activity:** >2.0 to 4.0 **High activity:** >4.0 to 10
Patient-driven composite tool + provider assessment	Clinical Disease Activity Index (CDAI)	0-76.0	Patient Global VAS; Provider Global VAS; 28-Tender Joint Count; 28-Swollen Joint Count	**Remission:** ≤2.8 **Low activity:** >2.8 to 10.0 **Moderate activity:** >10.0 to 22.0 **High activity:** >22
Patient-driven composite tool + provider assessment + laboratory acute phase reactants	Disease Activity Score with 28-joint counts with ESR or CRP (DAS28- ESR or DAS28-CRP)	0-9.4	Patient Global VAS; 28-Tender Joint Count; 28-Swollen Joint Count; ESR or CRP levels	**Remission:** <2.6 **Low activity:** ≥2.6 to <3.2 **Moderate activity:** ≥3.2 to ≤5.1 **High activity:** >5.1
	Simplified Disease Activity Index (SDAI)	0-86.0	Patient Global VAS; 28-Tender Joint Count; 28-Swollen Joint Count; CRP levels	**Remission:** ≤3.3 **Low activity:** >3.3 to ≤11.0 **Moderate activity:** >11.0 to ≤26 **High activity:** >26

CRP: C-reactive protein; ESR: erythrocyte sedimentation rate; HAQ: health assessment questionnaire; VAS: visual analog scale; MDHAQ: Multidimensional HAQ.

In contrast, one series found baseline factors associated with an increased likelihood of disease remission at 3 years with early treatment that included the following:[59]

- Low disease activity (DAS<4)
- Favorable health assessment (HAQ <1.25)
- Low CRP (<14.5 mg/l)
- Low joint tenderness (Ritchie score <17)
- Shorter duration of morning joint stiffness (<60 minutes)

The risk of radiographic progression has been associated with levels of disease activity. As such the use of disease activity measures of has become widespread in clinical practice. Validated RA scales categorize RA disease activity as either in remission, low, moderate, or high. In 2012, the ACR recommended 6 possible tools for point-of-care RA disease activity assessment. These recommendations were based on evidence that the measures reliably generated a single score that fell on a continuous disease activity scale and were realistic to implement in clinical practice (see Table 3). Current EULAR recommendations emphasize the use of validated composite disease activity measures that include joint counts.[56] According to these dual guidelines, remission is defined as meeting either the Boolean-based definition (patient must meet each of the following: TJC ≤1, SJC ≤1, CRP ≤1 mg/dl, and patient global assessment ≤1 on 0-10 scale) or index-based definitions (based on the SDAI or CDAI score).[56,60] Of note, since the publication of the ACR recommendations, other composite measures have been developed for use in the clinical setting.[20,35]

Treatment Strategies for Patients with RA

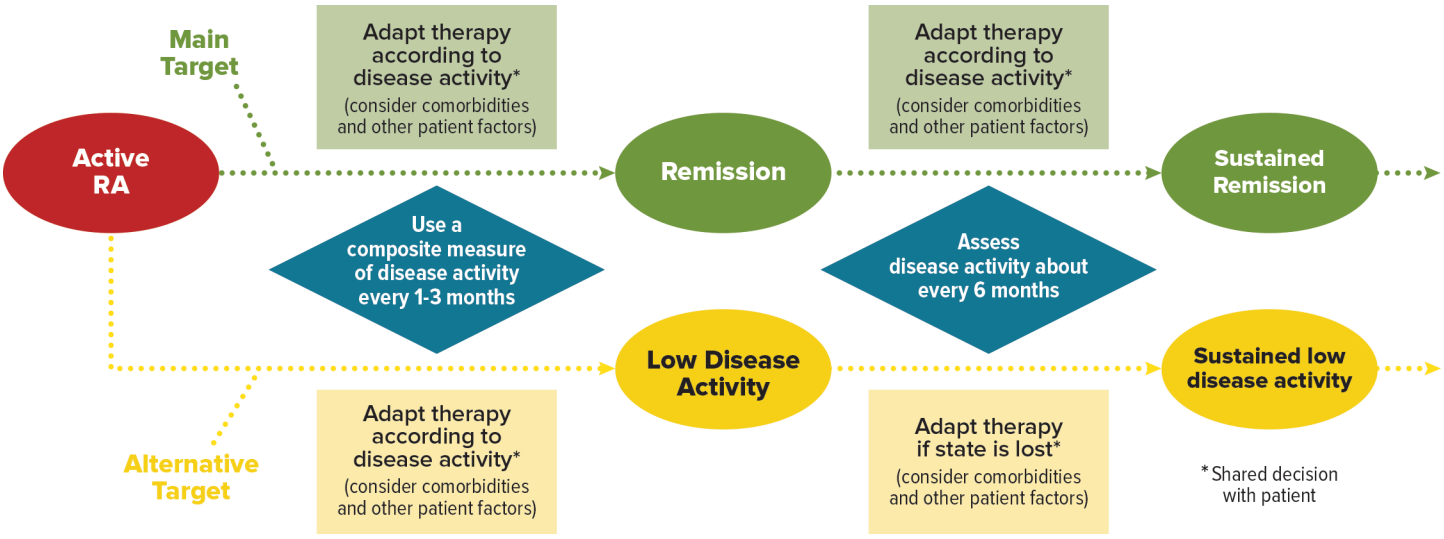
In clinical practice, disease activity and other patient factors, such as disease duration, progression of structural damage, comorbidities, and safety issues are typically used to guide treatment decisions.[35,56] As with other areas of clinical medicine, the determination of treatment targets and development of strategies to reach these goals should incorporate patient views and expectations.[61] Controlling the underlying inflammatory process can result in decreased pain, restored quality of life, and the prevention of joint destruction in patients with RA.[62] To achieve these goals, DMARD therapy should be initiated as soon as a diagnosis of RA is made.[35,56]

Treat to Target (T2T)

The Treat to Target (T2T) algorithm, originally developed in 2010 and updated in 2016, has been widely accepted as a model for delivering optimal care to patients with RA (see Figure 2). T2T is based on 4 overarching principles and 10 recommendations.[61,63]

A number of studies have compared patient outcomes using T2T compared vs. routine care and have consistently

Figure 2 *Treat to Target Algorithm for Patients with RA*



The Four Overarching Principles of Treat-to-Target Guidelines[61]

1. Promote shared decision making regarding treatment goals and decisions between the patient, rheumatologist, specialist nurse, and other members of the healthcare team
2. Maximizing patients' long-term quality of life through controlling symptoms, preventing structural damage, and normalizing function and involvement in social- and work-related activities is the primary treatment goal
3. Stopping/minimizing inflammation is the most important path to achieving treatment goals and optimizing outcomes
4. Optimize outcomes using the treatment to target approach by measuring disease activity and adjusting therapy accordingly

found that treating to a specific target of low-disease activity or remission is associated with better outcomes compared with routine care.[64-66]

A real-world analysis of patients receiving care at facilities participating in the Dutch Rheumatoid Arthritis Monitoring (DREAM) registry shed some light on the feasibility and utility of the T2T approach in daily clinical practice. In 2006, six of the hospitals in the DREAM consortium implemented a T2T strategy, effectively creating T2T and routine care cohorts, allowing for comparison of outcomes. Patients received treatment according to a DAS28-driven, step-up tight-control T2T model or received usual care. At one year, 55% of patients in the tight-control cohort achieved remission (DAS28<2.6) compared with 30% of patients in the usual care group; changes in DAS28 from baseline were -2.5 and -1.5, respectively; and the median time to remission was 25 weeks vs 52 weeks, respectively.[67] Furthermore, analysis of patients randomly selected from the DREAM T2T study cohort for chart review found adherence to the T2T strategy in the clinical setting was high, demonstrating its feasibility in daily clinical practice. DAS28 results were available for 97.9% of visits, of which DAS28 was assessed at least once every 3 months in 88.3% of visits.[68]

Additional recent evidence highlights the need to strive for treatment goals within predetermined timeframes. One study found that patients experiencing minor (58%) and major (85%) changes in SDAI or CDAI scores at 3 months after treatment initiation were highly likely to reach pre-set treatment targets at 6 months and achieve either low disease activity or clinical remission. Conversely, those patients who did not achieve at least a 50% improvement at 3 months had a substantially lower likelihood of reaching treatment targets at 6 months.[69]

Initial DMARD Therapy

Currently, DMARD monotherapy is recommended as first-line therapy in all DMARD-naïve patients. Methotrexate (MTX), a conventional DMARD, is considered the anchor treatment of choice for RA and should be initiated as soon as the diagnosis of RA is made unless contraindicated or patients develop early intolerance, in which case leflunomide, sulfasalazine, or hydroxychloroquine should be considered. The addition of glucocorticoids (GCs) when starting DMARD monotherapy may be considered as bridge therapy until DMARDs become effective, but should be tapered as rapidly as clinically feasible (usually within 3 months from treatment initiation). In patients who are not DMARD-naïve, the choice of optimal RA therapy should reflect current disease activity as well as past and current RA treatments.[35,56]

Subsequent DMARD Therapy

Clinical response to treatment with both conventional and biologic DMARDs is heterogeneous.[70] As such, frequent and routine assessment of disease activity (every 1-3 months) is a cornerstone of RA management. It is generally accepted that an agreed-upon treatment target should be reached approximately 6 months after treatment initiation, with therapy changed or optimized if insufficient improvement in disease activity is observed after 3 months. In the event of insufficient response to initial DMARD monotherapy, subsequent treatment decisions depend on patient preference, comorbidities, disease activity, response to treatment, insurance, and treatment history. Current guidelines provide a flexible framework for clinicians to choose an optimal and individualized therapy, with treatment options including combination conventional DMARD therapy, monotherapy with a different conventional DMARD, biologic DMARDs ± MTX (e.g. tumor necrosis factor inhibitor and non-TNF biologics), or a JAK inhibitor ± MTX. Of note, in addition to recommended laboratory monitoring, patients should undergo TB screening prior to initiating therapy with a biologic DMARD or JAK inhibitor.[35,56]

Much more on the treatment of RA will be included in forthcoming issues of *Rheumatology Nurse Practice* later this year.

Summary

It is widely accepted that early diagnosis and use of DMARDs in patients with RA is associated with improved patient outcomes. Whether newly referred patients arrive with suspected, presumptive, or definitive diagnoses of RA, many aspects of the first few office visits are similar. The initial office visits are integral to ensure an accurate and formal diagnosis of RA is made or confirmed and to establish baseline disease activity. Central to this process is developing therapeutic relationships with patients and their caregivers, providing ongoing education and support in a timely manner that is sensitive to information overload, and incorporating patient goals and preferences into treatment strategies.

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Ringing the Bell of Hope for Our Patients

by Iris Zink, MSN, NP, RN-BC

In October 2017, I met JP, a 66-year-old female patient, for the first time. During our initial meeting, JP reported that she had been recently seen by a new primary care doctor who then referred her to my rheumatology clinic thinking she had rheumatoid arthritis (RA) and neuropathy.

At our initial visit, JP reported symmetrical pain in all her joints that was worst in her hands and feet. Her chronic pain had started in her neck about 2 years ago, later radiating through the rest of her body. The pain had gotten progressively worse over time. She had >90 minutes of arm stiffness every morning and was having trouble with simple tasks around the house. She also reported difficulty sleeping due to both pain and diarrhea.

JP had recently retired from actively managing and owning 6 corporations and spent 3 days a week watching her two young grandchildren (6 and 8 years old). A smoker for several decades, JP still smoked a pack per day.

Her family history included Crohn's disease (mother) and gout (father). Her relevant medical history included being thrown from a car in an accident at age 13 and having a benign tumor removed from her abdomen at age 30. She also reported hepatitis of unknown type.

In addition, JP had diabetes than was poorly controlled, as evidenced by her most recent HbA1c of 7.3%. To help manage her pain, she was currently taking naproxen. A previous trial of tramadol was unsuccessful as JP said she "did not like the way it made me feel."

In addition to naproxen, JP's medication list included metformin, liraglutide, ezetimibe, losartan, conjugated estrogen, and carvedilol.

JP's presenting labs showed normal rheumatoid factor and positive anti-nuclear antibodies (ANA; 1:320 in a homogenous pattern). She also had positive extractable nuclear antigen (ENA) antibodies, although they were negative for SCL-70, anti-Sjögren's syndrome A, and anti-Sjögren's syndrome B. Her ribonucleoprotein (RNP) antibody levels were positive at 7.2 (normal: <0.9). Despite her positive ANA and RNP levels, JP denied the presence of fevers, night sweats, oral or nasal sores, hair loss, muscle weakness, and sun sensitivity/rash.

Upon physical exam, JP had 22/28 tender joints and some global synovitis in her proximal interphalangeal and metacarpophalangeal joints.

So in summary, we had a female older than age 60 with a family history of autoimmune disease and several positive disease markers who still smoked regularly.

What happened next? We started by ordering a full panel of labs that included a hepatitis panel, anti-citric citrullinated protein, and serum protein electrophoresis (to rule out monoclonal gammopathy and possible multiple myeloma). I also repeated testing of ANA and ENA antibodies. X-rays of JP's hands, feet, and chest were also ordered. Finally, I ordered a multibiomarker disease activity (Vectra) score due to a high suspicion of RA due to JP's persistent joint pain.

I went over with JP the results of her lab tests on her second visit to the office. Low B12 levels likely were the source of some of her neuropathy symptoms. ANA and RNP

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results remained positive, while other tests (ie, hepatitis panel, anti-CCP) came back negative. Her Vectra score was 48, demonstrating moderate disease activity. Foot and hand X-rays showed osteoarthritic changes, while the chest X-ray illustrated possible interstitial lung disease (ILD). Bone mineral density testing was normal.

This was a complicated combination of results to interpret. Based on her symmetrical pain, consistent morning stiffness, and other factors, my initial conclusion was that JP had seronegative RA.

I began by assuring JP that I thought I could help with her pain. We agreed to start with methotrexate 2.5 mg, at a conservative dose of 5 mg/week to see if she would tolerate the medication. Repeat labs were ordered in 4 weeks. Despite the chest X-ray findings, I did not feel that JP had ILD but rather displayed abnormalities due to her smoking habit—if I had concluded otherwise, we would not have started with methotrexate as the drug should be avoided in patients with ILD.

I encouraged JP to call immediately if she noted any side effects from methotrexate. To prevent the development of osteoporosis, we also put JP on citrated calcium and vitamin D supplementation. I also discussed with her the links between smoking and RA, encouraging her to at least cut back on her pack-a-day smoking habit.

JP agreed to our plan and expressed optimism that she would begin to again have fun with her grandchildren instead of struggling to get through the day with them.

Three months later—as we had agreed upon when starting her on methotrexate—JP was back in my office for an initial follow-up. Because methotrexate is only effective as monotherapy in about 40% of our RA patients,[1] and especially due to her complicated mix of comorbidities, I fully expected to hear that JP wasn't feeling much better and that we would need to consider adding a biologic to her regimen.

Surprise, surprise! JP told me that her pain was "75% better." Her attitude had clearly improved significantly as well. In fact, JP told me that she had been contemplating suicide prior to our first visit due to the persistent pain that was slowing her down and curtailing any enjoyment out of life. She said she had felt like a burden to her family and "didn't want to live like this anymore."

And now, just 3 months after the initiation of what we frequently consider a starter medication for the treatment of RA, JP was reporting that she "had her life back" and was no longer considering suicide. She was now able to look forward to the future instead of dreading it. Treating RA is certainly not "cookie cutter" medicine with consistent results from patient to patient. There are, like JP, some patients for whom methotrexate monotherapy can be effective in relieving pain for a long period of time.

We have a sign posted above a bell in the lobby of our office that reads, "If you feel better on your way out than when you came in, please let us know by ringing the bell." After this initial follow-up visit, JP rang the "satisfaction bell" for the first time. JP remains on 5 tablets per week of methotrexate for the time being. We'll continue to monitor her for any changes and adjust medications as needed. Knowing about her previous bout with depression and contemplation of suicide just gives me more motivation to keep JP thinking positive and feeling well.

Some days, it is hard to feel like we are making an impact on our patients. We see so many individuals with painful and debilitating chronic illnesses, and sometimes all we can offer is a listening ear and empathetic support. We all need motivation to keep going on these difficult days. Hearing the bell ring in our lobby gives me that little boost of energy I sometimes need, knowing that we changed the life of one more person for the better.

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Put Your Rheumatology Specs Away with New Patients

by Elizabeth Kirchner, CNP, RN-BC

Remember those "x-ray specs" they used to sell in the back of comic books? You'd send in your entire allowance, and in just 6-8 weeks, your x-ray specs would arrive in the mail, instantly allowing you to be able to see through walls, clothing, you name it.

Oh, you say you're too young to remember those? Well, humor me. Pretend you remember them. And just know that you totally missed out on some of the best ads in the history of advertising if you weren't a comic book fan in the 80s. These back-page ads weren't just for x-ray specs. They sold fake vomit! And chattering teeth! And whoopie cushions! It was a veritable plethora of stupid fun.

Unfortunately, the x-ray specs were, of course, fake. The point is that sometimes I feel like I've been walking around with "x-ray specs" on for a long time, only mine are called "Rheumatology Specs," and they make it seem perfectly natural to talk to co-workers about things like chronic disease, immunology, inflammation, and comorbidities. We hold entire conversations using strange acronyms, and because we are all wearing our Rheumatology Specs, this crazy stuff seems quite normal to us.

What we always need to remember, however, is that our patients never filled out that back-page order form, so they don't have those Rheumatology Specs, especially when they are newly diagnosed. Most of them didn't even know they had things called "synovia," and now they find out they not only have them, but they are inflamed and We.Must.Do.Something.About.That.Right.Away. Or worse, that weird "rosacea" they have had for years is actually lupus, and lots of people are suddenly talking to them in earnest about blood tests and kidney function and spinning urine when really all they wanted was for someone to give them a cream to make the rash go away. Now, here they are being told that, from now on, pregnancy might be "difficult." It's a wonder our patients ever come back for a second visit!

So what's the answer? Do we give every patient a pair of magical Rheumatology Specs along with detailed explanations of everything they probably never wanted to know? Do we try

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"We need to take off our Rheumatology Specs and just be human beings. It's up to us to sit down, look our patients in the eye, and ask, 'How can I help you today?'"

to get them to see the world the way we see it? I would argue that the answer to both of these questions is "no."

As anxious as we are to make our new patients understand the ins and outs of their chronic disease, I think the most important gift we can give our patients on their first (and possibly second, third, and even fourth) visit after their diagnosis has been made is silence. We need to take off our Rheumatology Specs and just be human beings. It's up to us to sit down, look our patients in the eye, and ask, "How can I help you today?"

Most patients will answer this question by asking about the issues that are most important to them. It's critical to remember that what is important to us, as caregivers, isn't worth a hill of beans compared to what's important to our patients. So when a patient who is newly diagnosed with rheumatoid arthritis wants to know if there is a vitamin he can take to make his body "fight off" the disease, guess what our conversation should be about? That's right—vitamins. Maybe at the end of the conversation we can slip in a plug for adherence to disease-modifying anti-rheumatic drugs, but only if the patient is ready to listen.

The first few visits with a new patient are so important for team-building and establishing trust. It can be helpful to start out by telling newly-diagnosed patients that they have just started a marathon and finding the answers to their pain and other issues will not happen next week or next month. There will be plenty of time for us to ask our patients questions. Once the pressure is off and their minds are somewhat clearer, we can put our Rheumatology Specs on—just for a few minutes at a time!—and get to work.

The Nervousness of the New Patient

by Carrie Beach, BSN, RN-BC

As an adult rheumatology nurse with nearly 15 years in the field, I have a certain comfort level when educating patients who have been newly diagnosed with rheumatoid arthritis (RA). I get a lot of the same questions over and over—"Will I be deformed?" or "Will I end up in a wheelchair?" or "What will these medications do to me?"—once patients receive their formal diagnosis. I'm comfortable and confident in how I respond to these questions in a manner that usually leaves patients feeling less distressed about their long-term prognosis.

Sometimes, though, we're all thrown a curveball that forces us to step out of our comfort zone. This is what happened to me recently with CT, a 17-year-old female who came to us as a referral from her primary care physician. CT had sudden-onset swelling and severe joint pain in several areas that had started about 3 months prior to her appointment. Just that quickly, she had gone from a healthy high school senior ready to go off to college to being scared and anxious about her future.

The pediatric nurses among you are probably saying, "Big deal. We see this all the time!" but for an adult rheumatology nurse like me whose new, younger patients are typically in their early 20s, I don't often encounter teenagers and their unique issues.

CT received a formal diagnosis of RA at her first visit. Given her age and absence of birth control use, our rheumatologist ruled out both methotrexate and leflunomide as treatment options, and we instead presented CT with information about adalimumab and infliximab. Because of the severity of her symptoms, we wanted to get her on treatment as soon as possible. After taking some time, CT and her mother eventually agreed to start with infliximab infusions since CT feared that she would not be able to use a self-injector due to a fear of needles. While we waited for insurance approval and openings in the infusion schedule, we gave CT a prednisone taper to help calm her symptoms.

This all happened on a Friday. I came into the office on a Monday with a message from CT's mother asking me to call her back. According to the message, CT and her family had taken the weekend to better digest all of the information we had provided to them, and CT's mother now had some further questions for me. As a parent of two young girls, I can only imagine how difficult it would be to process information about the diagnosis and treatment of a chronic disease like RA overnight. And so, knowing this would not be a quick and easy conversation, I waited until the end of the day when I could give this my undivided attention to return the call.

CT's mother initially had questions about what really happens in a patient with RA, what to expect with treatment, and other general topics. I reassured her that there were many RA patients who were able to live independently on a college campus with the disease. The conversation then shifted back to the initial decision about treatment—after further consideration, CT's family had decided that, despite serious reticence with needles, an injectable would be a better choice considering her college plans. After a subsequent discussion with my rheumatologist, we decided to start CT on golimumab rather than adalimumab due to the less frequent need for injections (once monthly vs. Q2W).

I scheduled a nursing visit with CT and her mom so that I could educate them more about golimumab, show CT how she would need to self-inject the medication, and answer any further questions they had. I don't often have time for an in-person consultation like this—a lot of my initial education for newly-diagnosed patients is done over the phone—but I felt like this was a unique case that perhaps triggered my maternal instincts. I wanted to make sure that CT and her mother had time to think about the questions they needed to have answered and to give them confidence with the self-injection process.

By the time of the appointment, the prednisone taper was beginning to have beneficial effects, giving CT hope that she would soon be able to return to her normal lifestyle. I gave CT instructions on the self-injection process, but I could tell she was extremely nervous. Her mother held CT's hand tightly when I handed her the autoinjector, but two clicks later, it was all over! CT beamed with pride and relief, being much more secure in her ability to do this on her own in the future.

While I would never have admitted as much in our office, I think I was more nervous than anyone that day. This was a teenage girl who just wanted to be a normal high school senior and go off to college like all of her friends. While it's almost second nature—although still challenging—for me to talk to newly-diagnosed adults about their disease and treatment options, I have minimal experience with teenaged patients. Stepping out of my comfort zone was certainly nerve wracking, but with the success of our interaction behind me, it's given me confidence for the future. As nurses, we should all strive to learn something new about ourselves from time to time and challenge ourselves to improve our capabilities. You never know when a patient like CT is going to walk through the door.

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Riding the Roller Coaster of a New Diagnosis

by Cathy Patty-Resk, MSN, RN, CPNP-PC

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Many years ago, in the pre-biologics era, a diagnosis of antibody-positive rheumatoid arthritis (RA) in children was rather tragic, often foretelling a future of significant joint deformities, disability, and chronic pain. Often, parents or grandparents of my current patients remember this era, which is why for them, hearing that their child/grandchild has been diagnosed with antibody-positive juvenile RA can be quite a blow.

Younger healthcare providers may only have seen photos of the deformities common in this bygone era in textbooks and therefore may not feel it is an issue that even needs to be discussed. However, because of the history many caregivers have with rheumatic diseases, their dismal potential view of the future should be addressed and addressed quickly. Only after they are reassured that their memories no longer represent a likely reality will they be able to truly hear what they are being told (a great resource for this is a website developed by the Arthritis Foundation called Kids Get Arthritis Too).[1]

We all know that RA in children can be successfully treated today with the use of biologic medications and that joint deformities only occur in children if there are long-standing problems with medication adherence (unless it a rare case where the patient doesn't improve on a battery of different drugs). Personally, I have not had a patient who did not respond at all to biologic therapy in 8 years, but it's important to note this disclaimer just in case.

When a new patient is coming into our office, often the parents, grandparents, and perhaps even the patient himself/herself has read about juvenile idiopathic arthritis (JIA) and adult RA. They are often aware that there are different types of arthritis with different prognostic indicators. Being able to give them a definitive diagnosis after we perform various testing often provides some level of comfort. For many patients and their caregivers, the diagnosis begins the first stage of grieving.

Grieving is quite normal in patients diagnosed with a chronic condition. Children may vacillate between different stages of grief through the years. They can both grieve about having a chronic disease and also for the "normal" childhood they wish they had. According to grief counselor Elisabeth Kübler-Ross, patients with a chronic disease as well as their caregivers typically pass through 5 stages of grief—denial, anger, bargaining, depression, and acceptance.[2] What can be tricky in patients with juvenile RA is that the child and caregivers are often at different stages

of grief, and it's up to the healthcare provider to be aware of where everyone stands to help them move through each phase. Children, of course, will react differently to the news of their diagnosis based on their age.

I have found it helpful to give parents who are really struggling with the grieving process significant behind-the-scenes support. For starters, I will often schedule a follow-up phone call a week after the formal diagnosis has been reached so that all parties have time to reflect on our initial discussion, talk through any key items that may be particularly important for their family, and come back to me to talk through their feelings and concerns. This call also allows me to get a sense of where the full team stands in the grieving process so that I can better anticipate future needs and share important clinical pearls. Getting parental support from the get-go is vital—after all, it is the parent who ends up being the team manager and cheerleader, giving their son or daughter the encouragement they need to successfully manage their disease.

Especially in the pediatric setting, the job of the rheumatology nurse is to give our patients and their families generous doses of hope. They are setting off on a lifelong roller coaster ride, and it's important to reinforce that patients will be able to pursue nearly any dream despite the ups, downs, and sharp curves that lay before them. There are so many well-known people who have succeeded despite being diagnosed with an autoimmune disease (Table 1)—with our care and patience, we'll hopefully soon be able to add more names to this list.

Table 1 *Famous People with RA*

Kristy McPherson	Professional golfer diagnosed with JIA at age 11
Glen Frey	Singer/guitarist for the Eagles
Christiaan Barnard	Surgeon who performed first heart transplant in 1967
Kathleen Turner	Actress
Lucille Ball	Actress
Aida Turturro	Actress (The Sopranos)
Seamus Mullen	World-renowned chef
Pierre August-Renoir	19th-century artist
Dorothy Hodgkin	Nobel Prize winning chemist who developed protein crystallography
Peter Paul Rubens	17th century artist
Raoul Dufy	Artist who participated in trial of corticosteroids in 1935 and painted a piece called la Cortisone which he gifted to the drug manufacturer because of how much it improved his arthritis

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