Rheumatology Nurses Society
Professional Education Series

ASKING THE HARD QUESTIONS:

What You Should Be Talking About with Newly Diagnosed Patients with

RHEUMATIC DISEASE

RNS

The Purpose of This Document

Rheumatology nurses and advanced practice providers (APPs), including nurse practitioners and physician assistants, work on a regular basis with patients who have been recently diagnosed with rheumatic disease. This is a key time for patients who are learning about what it means to live with their disease and who often need appropriate, evidence-based information to allay their concerns. This pocket guide includes a short summary of the evidence supporting of some of the most common issues you should be talking about with your newly diagnosed patients. We hope you find this guide informative and useful.

CONTENTS

How would you describe your pain?

In addition to being one of the defining symptoms of rheumatic disease, pain is also one of the most troubling symptoms for patients. Chronic pain undermines the ability to perform daily activities and has a significant impact on quality of life.[1] Although pain often accompanies inflammation, non-inflammatory pain may occur as well.[2]

One approach to pain assessment uses the acronym WILDA to ensure five key components are incorporated: <u>W</u>ords, <u>I</u>ntensity, <u>L</u>ocation, <u>D</u>uration, and <u>A</u>ggravating and alleviating factors.[3] Words used to describe pain help to differentiate types of pain, such as neuropathic, somatic, or visceral pain, and guide selection of appropriate interventions. Quantifying pain intensity using a pain scale

standardizes clinical assessment between providers and tracks its ups and downs over time. It is not uncommon for patients to have more than one area of pain, and asking patients to point to specific painful areas can be helpful. Describing the duration of pain can help identify exacerbations and breakthrough pain in those with chronic pain. Asking patients to identify things that make their pain better or worse and to discuss how pain affects daily activities can help with planning and managing pain interventions.

It is also important to keep in mind that psychosocial factors such as recent bad news, sadness, and depression can intensify pain. Finally, be sure to ask newly diagnosed patients about other symptoms that may be contributing to their pain, as well as any side effects of pain treatments. Some patients may stop taking analgesics altogether because of intolerable side effects.[3]

References

1. Sarzi-Puttini P, Atzeni F, Clauw DJ, Perrot S. The impact of pain on systemic rheumatic diseases. *Best Pract Res Clin Rheumatol.* 2015;29(1):1-5.
2. Lampa J. Pain without inflammation in rheumatic diseases. *Best Pract Res Clin Rheumatol.* 2019;33(3):101439.
3. Fink R. Pain assessment: the cornerstone to optimal pain management. *Proc (Bayl Univ Med Cent).* 2000;13(3):236-239.

Pain Assessment Guide[3]

TELL ME ABOUT YOUR PAIN

WORDS TO DESCRIBE PAIN

aching
stabbing
tender
tiring
numb
throbbing
gnawing
burning
penetrating
miserable
shooting
sharp
exhausting
nagging
unbearable
dull
crampy
radiating
deep
squeezing

Pain in other languages:

itami - Japanese
tang - Chinese
dau - Vietnamese
dolor - Spanish
douleur - French
bolno - Russian

INTENSITY (0-10)

If 0 is no pain and 10 is the worst pain imaginable, what is your pain now? ...in the last 24 hours?

LOCATION

Where is your pain?

DURATION

Is the pain always there?
Does the pain come and go? (Breakthrough Pain)
Do you have both types of pain?

AGGRAVATING AND ALLEVIATING FACTORS

What makes the pain better?
What makes the pain worse?

How does pain affect:

sleep
appetite
energy
activity
relationships
mood

Are you experiencing any other symptoms?

nausea/vomiting
constipation
itching
sleepiness/confusion
urinary retention
weakness

Things to check:

vital signs, past medication history, knowledge of pain, and use of noninvasive techniques

Do you use any dietary supplements or alternative medications to help manage your condition?

Treatment of musculoskeletal pain is one of the most common reasons for use of complementary and alternative medicine in the United States.[1] The use of dietary supplements is prevalent among individuals with arthritis.[2] Approximately 24% and 47% of individuals with gout and rheumatoid arthritis (RA), respectively, use dietary supplements compared with 18% of all adults.[3-5] There seems to be a willingness to "try anything" in the search for a cure among individuals with chronic disease.[6] In addition, a significant percentage of the general public is increasingly concerned about wellness and fitness, reject the use of chemicals,

and are suspicious of increasing costs of drugs by companies who they believe have ignored more natural products because their use cannot be patented.

Unfortunately, only a fraction of patients who use dietary supplements tell healthcare providers about the use of these products.[4,7] According to one published review, only 30% of RA patients report the use of dietary supplements to their clinicians, although 91% of patients who use dietary supplements receive concomitant pharmacologic treatment.[4] Given that the use of dietary supplements continues to rise among the general population, greater awareness of patient practices with regard to dietary supplements is warranted.[8] The American College of Rheumatology (ACR) recognizes the growing interest in complementary and alternative medicine and supports the integration of approaches that have been proven safe and effective.[9] Healthcare providers are encouraged to be proactive and inquire about patient interest and use of complementary health approaches instead of ignoring their use as “someone else’s problem.” Open discussions provide an opportunity for providers and patients to examine potential risks and benefits of specific approaches together. It also allows providers to direct patients to reliable sources of information such as the National Center for Complementary and Integrative Health and the Arthritis Foundation so that they can make more informed decisions about complementary health approaches.[9-11]

References

1. Barnes PM, Bloom B, Nahin RL. Complementary and alternative medicine use among adults and children: United States, 2007. *Natl Health Stat Report*. 2008(12):1-23.
2. Wilson PB. Dietary supplementation is more prevalent among adults with arthritis in the United States population. *Complement Ther Med*. 2016;29:152-7.
3. Chan E, House ME, Petrie KJ, Horne A, Taylor WJ, Dalbeth N. Complementary and alternative medicine use in patients with gout: a longitudinal observational study. *J Clin Rheumatol*. 2014;20(1):16-20.
4. DeSalvo JC, Skiba MB, Howe CL, Haiber KE, Funk JL. Natural product dietary supplement use by individuals with rheumatoid arthritis: A scoping review. *Arthritis Care Res (Hoboken)*. 2019;71(6):787-797.
5. Clarke TC, Black LI, Stussman BJ, Barnes PM, Nahin RL. Trends in the use of complementary health approaches among adults: United States, 2002–2012. National health statistics reports; no 79. Hyattsville, MD: National Center for Health Statistics. 2015. Available at www.cdc.gov/nchs/data/nhsr/nhsr079.pdf. Accessed February 10, 2020.
6. Binns CW, Lee MK, Lee AH. Problems and prospects: Public health regulation of dietary supplements. *Annu Rev Public Health*. 2018;39:403-420.

7. Busse JW, Heaton G, Wu P, Wilson KR, Mills EJ. Disclosure of natural product use to primary care physicians: a cross-sectional survey of naturopathic clinic attendees. *Mayo Clin Proc*. 2005;80(5):616-23.
8. Smith T, Kawa K, Eckl V, Johnson J. Sales of herbal dietary supplements in US increased 7.5% in 2015. *HerbalGram*. 2016:111;67-73.
9. American College of Rheumatology. Complementary and Alternative Medicine for Rheumatic Diseases. 2016. Available at www.rheumatology.org/Portals/0/Files/Complementary-and-Alternative-Medicine-for-Rheumatic-Diseases-Position-Statement.pdf. Accessed February 10, 2020.
10. National Center for Complementary and Integrative Health. Available at nccih.nih.gov. Accessed February 10, 2020.
11. Arthritis Foundation. Available at www.arthritis.org/home. Accessed February 10, 2020.

What type of exercise, if any, do you incorporate into your weekly routine?

Regular physical activity is key to improving and maintaining good health, especially in patients with rheumatic disease.[1] Not only does regular physical activity improve cardiovascular fitness and muscle strength, it also helps to reduce pain, increase energy, improve quality of life, and maintain a healthy body weight.[2,3] Even better, the benefits of physical activity start immediately after exercising and can be achieved even with brief periods of activity.

According to the U.S. Department of Health and Human Services, all adults, including those with chronic health conditions, should engage in at least 150 minutes of

moderate-intensity physical activity each week. This equates to 30 minutes a day, five times per week. Alternatively, individuals who are able can engage in vigorous-intensity aerobic activity or a combination of moderate- and vigorous-intensity exercise for 75-150 minutes spread throughout the week. Additionally, individuals should also incorporate strength training into their regimen two or more days each week.[1]

It is important to remember that not all patients will be able to meet these recommendations for physical activity, especially those with more severe rheumatic disease. Nevertheless, all individuals should avoid inactivity by engaging in regular physical activity to the best of their abilities.[1] One important caveat for patients with rheumatic disease: physical activities performed at a competitive or elite level, such as marathon running, are typically not recommended for individuals with inflammatory arthritis or joint problems as these may exacerbate their condition.[3]

Consulting with a healthcare professional or physical activity specialist can help individuals with chronic conditions match the types and amounts of activity appropriate to their abilities.[1] In general, recreational activities that are low impact, that can be performed without pain, and have a low risk of joint injury are recommended for individuals with arthritis.[1,3] Examples include walking, swimming, tai chi, and many muscle-strengthening exercises. Stretching

Phsycial Activity Recommendations for Adults[1]

ADULTS NEED A MIX OF PHYSICAL ACTIVITY TO STAY HEALTHY

MODERATE-INTENSITY AEROBIC ACTIVITY*

Anything that gets your heart beating faster counts.

at least
150
minutes per week

AND

MUSCLE-STRENGTHENING ACTIVITY

Do activities that make your muscles work harder than usual.

at least
2
days per week

**If you prefer vigorous-intensity aerobic activity (like running), aim for at least 75 minutes a week.*

If that's more than you can do right now, **do what you can.** Even 5 minutes of physical activity has real health benefits.

can also help reduce joint stiffness and improve range of motion.[1]

Therapeutic exercises may need to be prescribed to help individuals who have been inactive or address specific joints or body parts affected by their condition.

References

1. U.S. Department of Health and Human Services. Physical Activity Guidelines for Americans, 2nd edition. Washington, DC: US Department of Health and Human Services; 2018. Available at health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf. Accessed February 10, 2020.
2. Rausch Osthoff AK, Juhl CB, Knittle K, et al. Effects of exercise and physical activity promotion: meta-analysis informing the 2018 EULAR recommendations for physical activity in people with rheumatoid arthritis, spondyloarthritis and hip/knee osteoarthritis. *RMD Open*. 2018;4(2):e000713.
3. American College of Rheumatology. Exercise and Arthritis. Available at www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Living-Well-with-Rheumatic-Disease/Exercise-and-Arthritis. Updated June 2018. Accessed February 10, 2020.

Do you have any concerns about gaining or losing weight?

Obesity is common among patients with rheumatic disease.[1] Approximately one-quarter of patients with lupus, psoriatic arthritis, and RA, and more than half of all patients with gout, are obese.[2-5] In RA, which has been most extensively studied, obesity also appears to disproportionately affect women compared to men.[5,6]

Obesity is typically associated with poorer patient outcomes, especially among patients with chronic conditions.[7] Obese individuals diagnosed with rheumatic disease experience more frequent attacks, more joint pain, greater disability, and faster disease progression compared with non-obese patients.[8-11]

Fat tissue is no longer considered a passive bystander among patients with rheumatic disease, but is now known to actively produce a wide variety of adipokines that function in part by regulating the immune response.[12] Although data are still unclear, adipokines are suspected of contributing to the proinflammatory state and bone damage experienced by patients with rheumatic disease.[13,14]

At the same time, these inflammatory cytokines also play a role in the development of cardiovascular disease and diabetes, conditions for which patients with RA are known to be at increased risk.[14-16] Finally, obesity decreases the chance of achieving adequate disease control.[5,17] Certain disease-modifying antirheumatic drugs (DMARDs), including some anti-TNF inhibitors, do not work as well in patients who are obese.[18,19] Patients with rheumatic disease should therefore strive to maintain a healthy weight to better control their disease.

References

1. Nikiphorou E, Fragoulis GE. Inflammation, obesity and rheumatic disease: common mechanistic links. A narrative review. *Ther Adv Musculoskelet Dis.* 2018;10(8):157-167.
2. Stojan G, Fu W, Petri M. Body mass index and disease activity in systemic lupus erythematosus — a paradoxical relationship? Presented at 2017 ACR/ARHP Annual Meeting; November 3-8, 2017; San Diego, CA. Abstract 1634.

3. Queiro R, Lorenzo A, Tejón P, Coto P, Pardo E. Obesity in psoriatic arthritis: Comparative prevalence and associated factors. *Medicine (Baltimore).* 2019;98(28):e16400.
4. Zhu Y, Pandya B, Choi HK. Comorbidities of gout and hyperuricemia in the US general population: NHANES 2007-2008. *Am J Med*. 2012;125(7):679-687.
5. de Resende Guimarães MFB, Rodrigues CEM, Gomes KWP, et al. High prevalence of obesity in rheumatoid arthritis patients: association with disease activity, hypertension, dyslipidemia and diabetes, a multi-center study. *Adv Rheumatol.* 2019;59(1):44.
6. Albrecht K, Richter A, Callhoff J, et al. Body mass index distribution in rheumatoid arthritis: a collaborative analysis from three large German rheumatoid arthritis databases. *Arthritis Res Ther.* 2016;18:149.
7. Bray GA, Heisel WE, Afshin A, et al. The science of obesity management: An Endocrine Society scientific statement. *Endocr Rev.* 2018;39(2):79-132.
8. Nguyen UD, Zhang Y, Louie-Gao Q, et al. Obesity paradox in recurrent attacks of gout in observational studies: Clarification and remedy. *Arthritis Care Res (Hoboken).* 2017;69(4):561-566.
9. Klingberg E, Bilberg A, Björkman S, et al. Weight loss improves disease activity in patients with psoriatic arthritis and obesity: an interventional study. *Arthritis Res Ther*. 2019;21(1):17.
10. Vidal C, Barnetche T, Morel J, et al. Association of body mass index categories with disease activity and radiographic joint damage in rheumatoid arthritis: a systematic review and metaanalysis. *J Rheumatol*. 2015;42(12):2261-9.
11. Baker JF, England BR, Mikuls TR, et al. Obesity, weight loss, and progression of disability in rheumatoid arthritis. *Arthritis Care Res (Hoboken)*. 2018;70(12):1740-1747.

12. Versini M, Jeandel PY, Rosenthal E, Shoenfeld Y. Obesity in autoimmune diseases: not a passive bystander. *Autoimmun Rev*. 2014;13(9):981-1000.

13. Fatel ECS, Rosa FT, Simão ANC, Dichi I. Adipokines in rheumatoid arthritis. *Adv Rheumatol*. 2018;58(1):25.

14. Ruscitti P, Di Benedetto P, Berardicurti O, et al. Adipocytokines in rheumatoid arthritis: The hidden link between inflammation and cardiometabolic comorbidities. J *Immunol Res*. 2018;2018:8410182.

15. Nicolau J, Lequerré T, Bacquet H, Vittecoq O. Rheumatoid arthritis, insulin resistance, and diabetes. *Joint Bone Spine*. 2017;84(4):411-416.

16. Gualtierotti R, Ughi N, Marfia G, Ingegnoli F. Practical management of cardiovascular comorbidities in rheumatoid arthritis. *Rheumatol Ther*. 2017;4(2):293-308.

17. Sandberg ME, Bengtsson C, Källberg H, et al. Overweight decreases the chance of achieving good response and low disease activity in early rheumatoid arthritis. *Ann Rheum Dis*. 2014;73(11):2029-33.

18. Gremese E, Carletto A, Padovan M, et al. Obesity and reduction of the response rate to anti-tumor necrosis factor α in rheumatoid arthritis: an approach to a personalized medicine. *Arthritis Care Res (Hoboken)*. 2013;65(1):94-100.

19. Ottaviani S, Gardette A, Tubach F, et al. Body mass index and response to infliximab in rheumatoid arthritis. *Clin Exp Rheumatol*. 2015;33(4):478-483.

Is your disease interfering with your ability to work or participate in school?

According to the Centers for Disease Control and Prevention (CDC), 8 million working age adults (ages 18 to 64 years) are limited in their ability to work because of arthritis.[1] One study found that 20% of patients with RA stopped working within 2 years and 32% stopped within 5 years of diagnosis because of their disease.[2] For children with rheumatic disease, patients often take longer to complete schooling and are less likely to complete higher levels of education.[3,4] Another study found that working individuals with RA miss nearly 14 days of work each year compared to 10 days in adults without RA.[5] Even while at work, disease-related effects such as joint stiffness in fingers and wrists can limit patients' productivity.[6]

Individuals with a rheumatic disease may be able to continue working with job modifications that accommodate their unique symptoms. This means, of course, that patients requiring specific accommodations have to tell employers about their chronic health condition, which can be stressful. Individuals with rheumatic disease often fear being judged by peers, losing opportunities for advancement, and even being fired.[7]

Under the Americans with Disabilities Act, any company with 15 or more employees is required to provide reasonable accommodations to individuals with any impairment that substantially limits one or more major life activities.[8] Individuals can ask for modifications such as the following:[9,10]

- Ergonomic workstations
- Flexible hours or telecommuting during times of symptom flare
- Flexible dress code that allows for more comfortable clothing options
- Parking spaces that are close to the building

An occupational or physical therapist may be able to provide additional suggestions for workplace accommodations to patients and employers. A trial period can help to identify additional adjustments that may be needed.[10]

References

1. Centers for Disease Control and Prevention. Arthritis. Available at www.cdc.gov/chronicdisease/resources/publications/factsheets/arthritis.htm. Reviewed January 30, 2019. Accessed February 11, 2020.
2. Sokka T, Kautiainen H, Pincus T, et al.; QUEST-RA. Work disability remains a major problem in rheumatoid arthritis in the 2000s: data from 32 countries in the QUEST-RA study. *Arthritis Res Ther.* 2010;12(2):R42.
3. Díaz-Mendoza AC, Modesto Caballero C, Navarro-Cendejas J. Analysis of employment rate and social status in young adults with childhood-onset rheumatic disease in Catalonia. *Pediatr Rheumatol Online J.* 2015;13:29.
4. Schlichtiger J, Haas JP, Barth SEducation, et al. Education and employment in patients with juvenile idiopathic arthritis - a standardized comparison to the German general population. *Pediatr Rheumatol Online J.* 2017;15(1):45.
5. Gunnarsson C, Chen J, Rizzo JA, Ladapo JA, Naim A, Lofland JH. The employee absenteeism costs of rheumatoid arthritis: Evidence from US national survey data. *J Occup Environ Med.* 2015;57(6):635-42.
6. Boot CRL, de Wind A, van Vilsteren M, van der Beek AJ, van Schaardenburg D, Anema JR. One-year Predictors of presenteeism in workers with rheumatoid arthritis: Disease-related factors and characteristics of general health and work. *J Rheumatol*. 2018;45(6):766-770.
7. Gignac MA, Cao X. “Should I tell my employer and coworkers I have arthritis?” A longitudinal examination of self-disclosure in the workplace. *Arthritis Rheum.* 2009;61(12):1753-61.
8. Americans with Disabilities Act of 1990. Public. L. 101-336, 104 Stat. 328 (1990).
9. Arthritis Foundation. Rheumatoid arthritis in the workplace. Available at www.arthritis.org/health-wellness/healthy-living/daily-living/work-life-balance/rheumatoid-arthritis-in-the-workplace. Accessed February 11, 2020.
10. National Rheumatoid Arthritis Society. When an employee has rheumatoid arthritis. Available at www.nras.org.uk/data/files/Publications/When an Employee has Rheumatoid Arthritis -.pdf. April 2015. Accessed February 11, 2020.

Do you sometimes find that you feel down or depressed?

One out of every 8 patients with arthritis reports feeling depressed, and nearly 1 of every 4 patients has anxiety.[1] Asking patients about anxiety and depression is a key part of preventive care. The U.S. Preventive Services Task Force recommends depression screening for all individuals ages 12 years and older.[2] Regular screenings for depression and anxiety can lead to early identification of these issues, which translates into earlier care and potentially improved outcomes.[3]

Providers can use the two- and nine-item Patient Health Questionnaires (PHQ) to help guide their conversations with patients who they feel are showing signs of depression.[4] A score of 3 or more on the PHQ-2 is considered positive for depression.

PHQ Screening Tools for Depression[5]

Over the past two weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
PHQ				
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3
PHQ-9				
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3
Trouble falling or staying asleep, or sleeping too much	0	1	2	3
Feeling tired or having little energy	0	1	2	3
Poor appetite or overeating	0	1	2	3
Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
Moving or speaking so slowly that other people could have noticed; or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

PHQ-2 scoring: A score of ≥3 is considered a positive result. The PHQ-9 or a clinical interview should be completed for patients who screen positive.

PHQ-9 scoring: 1 to 4 points = minimal depression, 5 to 9 points = mild depression, 10 to 14 points = moderate depression, 15 to 19 points = moderately severe depression, 20 to 27 points = severe depression.

GAD-7 Screening Tool[7]

Over the past two weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
GAD-7				
Feeling nervous, anxious, or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Worrying too much about different things	0	1	2	3
Trouble relaxing	0	1	2	3
Being so restless that it is hard to sit still	0	1	2	3
Becoming easily annoyed or irritable	0	1	2	3
Feeling afraid as if something awful might happen	0	1	2	3

GAD scoring: 1-5 = mild anxiety, 6-10 = moderate anxiety, 11-15 = severe anxiety

Patients with a positive PHQ-2 result should undergo additional screening with the PHQ-9 or a clinical interview.

PHQ-9 scores provide a broader classification of results that range from minimal to severe depression. Patients with a positive PHQ-9 result should undergo a follow-up evaluation to confirm the diagnosis.[4,5]

Similar to the PHQ tools, the general anxiety disorder (GAD)-7 can be used to screen patients who may be showing signs of anxiety.[6,7] Scores of 5, 10, and 15 are designated cut-off values for probable mild, moderate, and severe anxiety, respectively.[7] Further evaluation is recommended for patients with scores of 10 or more.

References

1. Guglielmo D, Hootman JM, Boring MA, et al. Symptoms of anxiety and depression among adults with arthritis — United States, 2015–2017. *MMWR Morb Mortal Wkly Rep.* 2018;67(39):1081–1087.
2. Centers for Disease Control and Prevention. The arthritis-mental health connection. Available at www.cdc.gov/features/arthritis-mental-health/index.html. Reviewed October 12, 2018. Accessed February 11, 2020.
3. US Preventive Services Task Force. Recommendations for primary care practice. Available at www.uspreventiveservicestaskforce.org/Page/Name/recommendations. Accessed February 11, 2020.
4. Maurer DM, Raymond TJ, Davis BN. Depression: Screening and diagnosis. *Am Fam Physician.* 2018;98(8):508-515.
5. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders.* 5th ed. Washington, DC: American Psychiatric Association; 2013.
6. Substance Abuse and Mental Health Services Administration and US Department of Health and Human Services Health Resources and Services Administration. SAMHSA-HRSA Center for Integrated Health Solutions. Available at www.integration.samhsa.gov/clinical-practice/screening-tools. Accessed February 11, 2020.
7. Spitzer RL, Kroenke K, Williams JB, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med.* 2006;166(10):1092-7.

How many times each week do you think you miss a dose of your prescribed medications?

Studies of patients with rheumatic disease indicate that medication adherence rates range from 15-80%.[1-5] This means that patients miss taking prescribed doses of medications anywhere between once a week to as many as five days each week. Not only can medication nonadherence lead to poor disease control, but it can also contribute to an individual's perception that they are less capable of engaging in other healthy behaviors such as eating a healthy diet and engaging in physical activity. It may also restrict their ability to openly communicate with their providers.[6]

Reasons for nonadherence vary, and there is often more than a single cause.[7] Poor adherence can frequently be caused by patients' beliefs about their disease and medication, including doubt regarding the necessity for medication to treat their condition, differences between medications, potential side effects, how or when to take medications, and perceptions that medications are failing to control pain and inflammation.[6,8] Forgetfulness, running out of medication, side effects, life events, and the presence of other comorbid illnesses can also contribute to missed doses.[7,8]

Understanding that medication adherence is a healthcare team priority may help motivate patients to achieve adherence goals.[9] Patients are more likely to prioritize tackling self-management issues such as medication adherence if they view it as the following:[9]

- Relatively easy or realistic to overcome
- Important and/or pressing
- A comfortable topic to discuss
- Something that they have been told to or think they should work on

Research also shows that providers who directly address patient concerns about their condition and its treatment are more likely to be adherent to prescribed therapy.[10] These discussions are aided when patients feel comfortable with healthcare team members and view them as ready to assist in their care.[9]

References

1. van den Bemt BJ, Zwikker HE, van den Ende CH. Medication adherence in patients with rheumatoid arthritis: a critical appraisal of the existing literature. *Expert Rev Clin Immunol*. 2012;8(4):337–51.
2. Murage MJ, Tongbram V, Feldman SR, et al. Medication adherence and persistence in patients with rheumatoid arthritis, psoriasis, and psoriatic arthritis: a systematic literature review. *Patient Prefer Adherence.* 2018;12:1483–1503.
3. Oelke KR, Chambenoit O, Majjhoo AQ, Gray S, Higgins K, Hur P. Persistence and adherence of biologics in US patients with psoriatic arthritis: analyses from a claims database. *J Comp Eff Res*. 2019;8(8):607-621.
4. Scheepers LEJM, van Onna M, Stehouwer CDA, Singh JA, Arts ICW, Boonen A. Medication adherence among patients with gout: A systematic review and meta-analysis. *Semin Arthritis Rheum*. 2018;47(5):689-702.
5. Costedoat-Chalumeau N, Pouchot J, Guettrot-Imbert G, et al. Adherence to treatment in systemic lupus erythematosus patients. *Best Pract Res Clin Rheumatol*. 2013;27(3):329-340.
6. Oshotse C, Zullig LL, Bosworth HB, Tu P, Lin C. Self-Efficacy and adherence behaviors in rheumatoid arthritis patients. *Prev Chronic Dis*. 2018;15:E127.
7. Marengo MF, Suarez-Almazor ME. Improving treatment adherence in patients with rheumatoid arthritis: what are the options? *Int J Clin Rheumtol*. 2015;10(5):345–356.
8. Hope HF, Hyrich KL, Anderson J, et al.; RAMS co-investigators. The predictors of and reasons for non-adherence in an observational cohort of patients with rheumatoid arthritis commencing methotrexate. *Rheumatology (Oxford)*. 2020;59(1):213-223.
9. Hessler DM, Fisher L, Bowyer V, et al. Self-management support for chronic disease in primary care: frequency of patient self-management problems and patient reported priorities, and alignment with ultimate behavior goal selection. *BMC Fam Pract*. 2019;20(1):120.
10. Phillips LA, Leventhal H, Leventhal EA. Physicians' communication of the common-sense self-regulation model results in greater reported adherence than physicians' use of interpersonal skills. *Br J Health Psychol*. 2012;17(2):244-57.

Do you anticipate potentially having trouble paying for your medications?

Research shows that out-of-pocket costs for disease modifying antirheumatic drugs (DMARDs) and biologic therapies have steadily increased over the past several years. In 2013, RA patients paid an average of $145 out-of-pocket per prescription.[1] More recently, a 2019 analysis by the Kaiser Family Foundation showed that Medicare patients with RA were expected to spend between $4,400 to $5,500 over the course of a year on specialty medications (ie, biologics).[2] Unfortunately, the higher the out-of-pocket cost, the less likely patients are to fill their prescriptions.[3]

At the same time, approximately one-third of patients with RA or psoriatic arthritis face access restrictions to DMARDs by insurance plans requiring prior authorization or step-therapy approaches.[4] Private payers frequently have coverage policies that are more restrictive than corresponding U.S. Food and Drug Administration labels or American College of Rheumatology recommendations.[5] Failing to try multiple rounds of less expensive drugs is one of the more common reasons for denying coverage for biologics.[6]

Patient support programs from drug manufacturers are available for most biologics and small molecules used to treat rheumatic disease.[6,7] These specialty programs have been shown to reduce medical costs as well as improve medication adherence and persistence.[8]

Programs offer help with navigating insurance coverage and issues with reimbursement. Often, financial assistance is available. The type of financial assistance varies between programs, but co-pay cards, prescription rebates, patient assistance programs, and help with identifying foundations and nonprofit organizations that offer patient financial support are common. Most programs can be found by visiting drug manufacturer websites.

Medication	Manufacturer Program	Phone Number
Abatacept (Orencia)	Orencia On Call	1.800.ORENCIA (1.800.673.6242)
Adalimumab (Humira)	Humira Complete	1.800.4HUMIRA (1.800.448.6472)
Anakinra (Kineret)	Kineret ON TRACK and Kineret on TRACK Guidance	1.866.547.0644
Belimumab (Benlysta)	Benlysta Gateway	1.877.4BENLYSTA (1.877.423.6597)
Certolizumab pegol (Cimzia)	CIMplicity ®	1.844.599.CARE (1.844.599.2273)
Etanercept (Enbrel)	Enbrel Support™	1.888.4ENBREL (1.888.436.2735)
Golimumab (Simponi)	Janssen CarePath	1.877.CarePath (1.877.227.3728)
Infliximab (Remicade)	Janssen CarePath	1.877.CarePath (1.877.227.3728)
Ixekizumab (Taltz)	Taltz® Together™	1.844.344.8108
Pegloticase (Krystexxa)	KRYSTEXXAConnect	1.888.KRYSTEXXA (1.888.579.7839)
Rituximab (Rituxan)	Genentech Rheumatology Access Solutions®	1.877.474.8892
Sarilumab (Kevzara)	KevzaraConnect	1.844.COSENTYX (1.844.267.3689)
Secukinumab (Cosentyx)	COSENTYX® Connect	1.844.COSENTYX (1.844.267.3689)
Tocilizumab (Actemra)	Genentech Rheumatology Access Solutions® ACTEMRA & You	1.855.RACOPAY (1.855.722.6729)
Tofacitinib (Xeljanz)	XELSource Financial Help Xeljanz + You	1.855.4XELJANZ (1.855.493.5526)
Ustekinumab (Stelara)	Janssen CarePath	1.877.CarePath (1.877.227.3728)

Patient and Provides Resources Website
www.orencia.com/savings-support/on-call-patient-support
www.humira.com/humira-complete www.humirapro.com/humira-complete
www.kineretrx.com/ra/kineret-on-track www.kineretrx.com/hcp/practice-support
www.kineretrx.com/hcp/practice-support gskpro.com/en-us/products/benlysta/access-support/accessing-benlysta/
www.cimzia.com/cimplicity-program www.cimziahcp.com/patient-support
www.enbrel.com/support/enbrel-support-program www.enbrel.com/hcp/professional-resources
www.janssencarepath.com/patient/simponi/patient-support www.janssencarepath.com/hcp/simponi
www.remicade.com/rheumatoid-arthritis/remicade-support/medication-cost-support/commercial-insurance www.janssencarepath.com/hcp/remicade
www.taltz.com/patient-support www.taltz.com/hcp/enrollment-forms
https://www.krystexxa.com/support/ www.krystexxahcp.com/reimbursement-center
www.rituxanforra.com www.rituxanforra-hcp.com
https://connect.cosentyx.com/cosentyxsignup/# https://www.cosentyxhcp.com/
https://connect.cosentyx.com/cosentyxsignup/# https://www.cosentyxhcp.com/
www.actemra.com www.actemrahcp.com
ra.xeljanz.com/rheumatoid-arthritis-support-resources www1.pfizerpro.com/product/xeljanz/ra
https://www.janssencarepath.com/hcp/stelara

References

1. Atzinger CB, Guo JJ. Biologic disease-modifying antirheumatic drugs in a national, privately insured population: Utilization, expenditures, and price trends. *Am Health Drug Benefits*. 2017;10(1):27-36.
2. Cubanski J, Koma W, Neuman T. The out-of-pocket cost burden for specialty drugs in Medicare Part D in 2019. Available at www.kff.org/report-section/the-out-of-pocket-cost-burden-for-specialty-drugs-in-medicare-part-d-in-2019-findings. Published February 1, 2019. Accessed February 24, 2020.
3. Hopson S, Saverno K, Liu LZ, et al. Impact of out-of-pocket costs on prescription fills among new initiators of biologic therapies for rheumatoid arthritis. *J Manag Care Spec Pharm*. 2016;22(2):122-30.
4. Boytsov N, Zhang X, Evans KA, Johnson BH. Impact of plan-level access restrictions on effectiveness of biologics among patients with rheumatoid or psoriatic arthritis. *Pharmacoecon Open.* 2020;4(1):105-117.
5. Chambers JD, Wilkinson CL, Anderson JE, Chenoweth MD. Variation in private payer coverage of rheumatoid arthritis drugs. *J Manag Care Spec Pharm.* 2016;22(10):1176-1181.
6. Abdelnabi M, Patel A, Rengifo-Pardo M, Ehrlich A. Insurance coverage of biologics for moderate-to-severe psoriasis: A retrospective, observational 5-year chart review. *Am J Clin Dermatol*. 2016;17(4):421-424.
7. Ganguli A, Clewell J, Shillington AC. The impact of patient support programs on adherence, clinical, humanistic, and economic patient outcomes: a targeted systematic review. *Patient Prefer Adherence.* 2016;10:711-25.
8. Rubin DT, Mittal M, Davis M, Johnson S, Chao J, Skup M. Impact of a patient support program on patient adherence to adalimumab and direct medical costs in Crohn's disease, ulcerative colitis, rheumatoid arthritis, psoriasis, psoriatic arthritis, and ankylosing spondylitis. *J Manag Care Spec Pharm*. 2017;23(8):859-867.

Do you know if you are up to date on recommended vaccinations, such as a flu shot, pneumonia vaccine, and tetanus vaccine? Do you have a record of these?

Immunizations are especially important for patients with rheumatic disease. Many of the immunosuppressive agents used to treat these conditions interfere with the body's inflammatory response. While this activity is helpful in relieving painful inflammation, it can also inhibit the body's ability to fight off infections.[1]

Vaccination rates among patients with rheumatic disease remain low.[2-4] One large cohort study found

that approximately two-thirds of patients with RA did not receive annual influenza vaccinations and less than half of patients had received pneumococcal vaccinations.[4] Receiving a vaccination prescription from a healthcare provider is one proven way to improve these rates, making it an important component of initial patient discussions.[5,6]

Individuals with rheumatic disease who are planning to begin or are already receiving immunosuppressive treatment should receive the following inactivated vaccines:[7-9]

- Pneumococcal 13-valent conjugate vaccine (PCV13)
- Pneumococcal 23-valent polysaccharide vaccine (PPSV23)
- Annual influenza vaccine

Patients with additional risk factors, such as those with HIV infection or high sexual exposure risk, intravenous drug users, and healthcare professionals, should receive hepatitis A, hepatitis B, meningococcal serogroups A, C, W, Y, and meningococcal serogroup B vaccines.[7,9] Individuals who are not current with other routinely recommended immunizations, including tetanus and diphtheria (Td) or tetanus, diphtheria, and pertussis (Tdap), and human papillomavirus vaccine, should undergo immunization. The exceptions to this are for live vaccines such as measles, mumps, and rubella (MMR), varicella (VAR), and the live zoster vaccine (ZVL) due to the fact that immune suppressed individuals may be at greater risk for adverse reactions with live attenuated vaccines.[9]

American College of Rheumatology guidelines specifically recommend that patients with RA who are ≥50 years of age be given the herpes zoster vaccine prior to beginning biologic therapy or tofacitinib.[7] By asking about vaccination histories, providers can improve coverage and reduce the risk of vaccine-preventable illnesses in their patients.

References

1. Rondaan C, Furer V, Heijstek MW, et al. Efficacy, immunogenicity and safety of vaccination in adult patients with autoimmune inflammatory rheumatic diseases: a systematic literature review for the 2019 update of EULAR recommendations. *RMD Open.* 2019;5(2):e001035.
2. Hmamouchi I, Winthrop K, Launay O, Dougados M. Low rate of influenza and pneumococcal vaccine coverage in rheumatoid arthritis: data from the international COMORA cohort. *Vaccine*. 2015;33(12):1446-1452.
3. Subesinghe S, Rutherford AI, Ibrahim F, Harris H, Galloway J. A large two-centre study into rates of influenza and pneumococcal vaccination and infection burden in rheumatoid arthritis in the UK. *BMC Musculoskelet Disord.* 2016;17:322.

4. Costello R, Winthrop KL, Pye SR, Brown B, Dixon WG. Influenza and pneumococcal vaccination uptake in patients with rheumatoid arthritis treated with immunosuppressive therapy in the UK: A retrospective cohort study using data from the Clinical Practice Research Datalink. *PLoS One.* 2016;11(4):e0153848.
5. Lejri-El Euchi H, Chirpaz E, Foucher A, et al. Vaccination against influenza and pneumococcal infections in patients with autoimmune disorders under biological therapy: Coverage and attitudes in patients and physicians. *Eur J Intern Med*. 2019;69:25-31.
6. Gosselin Boucher V, Colmegna I, Gemme C, Labbe S, Pelaez S, Lavoie KL. Interventions to improve vaccine acceptance among rheumatoid arthritis patients: a systematic review. *Clin Rheumatol.* 2019;38(6):1537-1544.
7. Singh JA, Saag KG, Bridges SL Jr, et al.; American College of Rheumatology. 2015 American College of Rheumatology guideline for the treatment of rheumatoid arthritis. *Arthritis Care Res (Hoboken).* 2016;68(1):1-25.
8. Singh JA, Guyatt G, Ogdie A, et al. Special Article: 2018 American College of Rheumatology/National Psoriasis Foundation guideline for the treatment of psoriatic arthritis. *Arthritis Rheumatol.* 2019;71(1):5-32.
9. Centers for Disease Control and Prevention. Immunization schedules. Available at www.cdc.gov/vaccines/schedules/hcp/imz/adult.html. Reviewed February 3, 2020. Accessed February 12, 2020.
10. Centers for Disease Control and Prevention. Vaccine Recommendations and guidelines of the ACIP: Altered immunocompetence. Available at www.cdc.gov/vaccines/hcp/acip-recs/general-recs/immunocompetence.html. Reviewed August 20, 2019. Accessed February 12, 2020.

Do you have any travel plans in the next year?

Whether traveling for business or pleasure, individuals with rheumatic disease should take steps to plan ahead to make their experiences smoother and more enjoyable.[1,2]

Websites from organizations such as the Arthritis Foundation and the Society for Accessible Travel & Hospitality provide a variety of tips and practical advice on travel.[2,3] Many accommodations are available that can make travel easier if individuals ask about them.

Prior to travel, healthcare providers should remember to remind patients about their medication requirements. This includes making sure patients have enough medication to take with them, that they know how to adapt medication schedules

to changes in time zones and how to properly travel with medications (ie, keeping medications in carry-on items and not checked baggage), that they have a plan for storing medications that require refrigeration during travel and at their destination, and that they know what to do if medications are lost or run out. Patients should carry information about their condition with them, along with a list of current medications and health insurance information. Some patients who use injectable medications may need a note from a prescribing clinician in case they are asked about these injectables during airport security screenings.[1,4]

If foreign travel is planned, providers and patients should review any immunizations that are recommended for intended destinations. In general, live vaccines such as yellow fever and MMR vaccines are contraindicated in immunosuppressed individuals. Itinerary changes should be strongly considered for immune compromised travelers who are unable to receive recommended immunizations.[5]

Finally, patients should be provided with basic information that can help make travel more comfortable. You may want to advise patients to move around and stretch, even while seated, to prevent stiffness. Suggest wearing comfortable shoes and using rolling suitcases with four wheels that spin on the bottom. Finally, remind them to not be afraid to ask for help if they need it.[1,4]

References

1. Arthritis Foundation. 8 Tips for pain-free travel. Available at www.arthritis.org/health-wellness/healthy-living/daily-living/life-hacks-tips/8-tips-for-pain-free-travel. Accessed February 12, 2020.
2. Arthritis Foundation. Available at www.arthritis.org/home. Accessed February 12, 2020.
3. Society for Accessible Travel and Hospitality. Available at sath.org/index.php. Accessed February 12, 2020.
4. Donohue M. Travel requires special precautions if you have rheumatoid arthritis. US News and World Report. August 4, 2017. Available at health.usnews.com/health-care/patient-advice/articles/2017-08-04/travel-requires-special-precautions-if-you-have-rheumatoid-arthritis. Accessed February 12, 2020.
5. Nelson Kotton C, Kroger AT, Freedman DO. Approach to the immunocompromised traveler. Centers for Disease Control and Prevention. Available at wwwnc.cdc.gov/travel/yellowbook/2020/travelers-with-additional-considerations/immunocompromised-travelers. Accessed February 12, 2020.

Are you planning to try to conceive within the next 12 months?

Rheumatic disease and certain treatments used to control disease are known to affect reproduction and fetal health. Compared with healthy individuals, women with rheumatic disease have fewer births, an overall shorter period of reproduction, and more difficulty achieving subsequent pregnancies.[1] One large study found that among a group of women with RA who were trying to become pregnant, 42% took more than 12 months to conceive.[2]

In men, disease data surrounding infertility remain less clear.[3] However, several drugs have the potential to affect sperm cells. In particular, men should consider discontinuing cyclophosphamide, methotrexate, and sulfasalazine for

a period of 3 months prior to conception.[2,3] Men should also consider discontinuing leflunomide.[3] Leflunomide can remain in the body for up to 2 years, requiring a cholestyramine washout to reduce drug levels.[3,4]

Most women with rheumatic disease can have successful pregnancies with careful medical and obstetric management. However, patients must be aware that possible complications for both mother and child can arise. In particular, diseases that can affect the kidneys, such as lupus and antiphospholipid syndrome, are more likely to cause issues with pregnancy than others.[5]

For women wishing to conceive, the ACR recommends postponing pregnancy until the patient's disease is well controlled for at least 3-6 months.[5] Women should discontinue medications with known deleterious effects on pregnancy and undergo a washout, if necessary, at least 3 months prior to conceiving.[3] As long as medications are not harmful to the child, women should remain on their current treatments to prevent disease flares during pregnancy. Although safety information is incomplete, there are several available medications that are considered acceptable for use during pregnancy and while nursing.[5] Newer medications may lack recommendations regarding use during pregnancy.[3]

Medication Guidance During Pregnancy and Lactation[5]

Medication	Safe to Use During Pregnancy?	Safe to Use During Lactation?
NSAID	Yes (avoid after 32 weeks)	Yes
Sulfasalazine	Yes	Yes
Antimalarials	Yes	Yes
Corticosteroids	Yes	Yes
Cyclosporine	Yes	Probably Yes
Azathioprine	Yes	Probably Yes
Mycophenolate	No	No
Methotrexate	No	No
Cyclophosphamide	No	No
Anti-TNFs	Yes	Yes
Rituximab	No	No
Warfarin	No (with caution, only after first trimester)	Yes
Heparin	Yes	Yes

References

1. Bazzani C, Andreoli L, Agosti M, Nalli C, Tincani A. Antirheumatic drugs and reproduction in women and men with chronic arthritis. *RMD Open*. 2015;1(Suppl 1):e000048.
2. Brouwer J, Hazes JM, Laven JS, Dolhain RJ. Fertility in women with rheumatoid arthritis: influence of disease activity and medication. *Ann Rheum Dis*. 2015;74(10):1836–41.
3. Hunt N, Talabi MB. Family planning and rheumatoid arthritis. *Curr Rheumatol Rep*. 2019;21(5):16.
4. ARAVA® (leflunomide) [package insert]. Bridgewater, NJ: sanofi-aventis U.S. LLC; 2016.
5. American College of Rheumatology. Pregnancy and rheumatic disease. Available at www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Living-Well-with-Rheumatic-Disease/Pregnancy-Rheumatic-Disease.

What questions do you have for me?

A strong partnership between patients and their providers is increasingly recognized as a key component to managing rheumatic disease. Tailored education empowers patients and facilitates a process of shared decision-making that in turn informs all aspects of disease management.[1,2] Communication is central to this process and no visit, therefore, should end before patients have a chance to ask their providers any questions on their mind.

Research shows that the nature of patient interactions with providers can have a significant impact on patient outcomes.[3,4] Active and positive patient participation is associated with feelings of being understood, increased participation in the decision-making process, greater treatment satisfaction, and more

positive beliefs about current and future health. In turn, this leads to better control of inflammation, pain, and other symptoms, along with fewer medication-related side effects.[3] Engaging patients is therefore critical for establishing a trusting patient-provider relationship that allows patients to feel confident about their care.[5]

References

1. Nikiphorou E, Alunno A, Carmona L, Kouloumas M, Bijlsma J, Cutolo M. Patient-physician collaboration in rheumatology: a necessity. *RMD Open.* 2017;3(1):e000499.
2. Smolen JS, Landewé , Bijlsma J, et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update. *Ann Rheum Dis.* 2017;76(6):960-977.
3. Georgopoulou S, Prothero L, D’Cruz DP. Physician-patient communication in rheumatology: a systematic review. *Rheumatol Int.* 2018;38(5):763-775.
4. Robert Wood Johnson Foundation. Preparing to Import a Successful Model for an Interactive Disease Registry System to the United States. February 28, 2015. Available at www.rwjf.org/en/library/research/2015/02/preparing-to-import-a-successful-model-for-an-interactive-diseas.html. Accessed February 17, 2020.
5. Krist AH, Tong ST, Aycock RA, Longo DR. Engaging patients in decision-making and behavior change to promote prevention. *Stud Health Technol Inform.* 2017;240:284-302.

Supported by educational grants
from **AbbVie, Gilead,** and **Pfizer.**

BE THE RESOURCE THEY NEED.

RNSnurse.org

RNS RHEUMATOLOGY NURSES SOCIETY™

8437 Tuttle Avenue - Suite 404 / Sarasota, FL 34243