



RHEUMATOLOGY NURSE PRACTICE

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VOLUME 6 / ISSUE 2

- + How exactly should we define the term “health disparities?”
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- + What are some of the strategies that providers and practices can take to remove the barriers that cause health disparities among specific racial/ethnic groups?
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HEALTH DISPARITIES

In the Management of Psoriatic Arthritis

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ACTIVITY DESCRIPTION

In this issue of *Rheumatology Nurse Practice*, we will review what is known about disparities in PsA prevalence, treatment, and outcomes among different racial/ethnic groups. We will also discuss strategies that rheumatology specialists can use to deliver the type of high-quality, inclusive care needed to reduce healthcare disparities.

LEARNING OBJECTIVES

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

- Define the term “health disparities”
- Discuss reasons why psoriatic arthritis (PsA) is underdiagnosed and undertreated in patients of color
- Develop strategies to create a more culturally competent professional practice
- Identify resources that are available to assist in addressing specific health disparities among patients with PsA

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HEALTH DISPARITIES

In the Management of Psoriatic Arthritis

Healthcare workers are becoming increasingly concerned with the dramatic health disparities in the United States (see Figure 1), especially those related to race. From heart disease to breast cancer to maternal mortality, people of color experience poorer health outcomes than the general population.¹ Today, a Black woman in the United States is 22% more likely to die from heart disease, 71% more likely to die from cervical cancer, and 243% more likely to die from pregnancy- or childbirth-related causes than a White woman.²

Figure 1

What Are Health Disparities?

“A particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”

- Healthy People 2020⁵⁵

“Preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.”

- U.S. Centers for Disease Control & Prevention⁵⁶

When it comes to health disparities, psoriatic arthritis (PsA) is no exception. In recent years, great strides have been made in the care of patients with PsA. Many experts now consider remission a reasonable treatment goal for many patients with PsA,³ especially if therapy is initiated early in the course of disease. However, too many patients of color are not benefiting from these advances. Research shows they experience more severe disease and worse quality of life than White patients.^{4,5} Moreover, the impact of PsA extends beyond pain, functional limitations, and emotional distress. Because PsA is associated with a significant individual, family, and societal economic burden,⁶ addressing healthcare disparities for this condition is also a matter of economic justice.

Healthcare providers have a key role to play in ameliorating health disparities, including for PsA, as these disparities reflect differences in the quality of healthcare delivered to people of color.⁷ In fact, for roughly 40% of

healthcare quality measures tracked by the Agency for Healthcare Research and Quality, Blacks and American Indians/Alaska Natives receive worse care than Whites.⁸ The results are similar for Hispanics and Native Hawaiians/Pacific Islanders, who receive worse care than Whites for one-third or more of quality measures.

Consequently, dismantling structural racism to reduce health disparities has become a major concern in both nursing and rheumatology. In 2020, the American Public Health Association⁹ and the American Medical Association¹⁰ released statements identifying racism as a public health threat and committed to working toward dismantling structural racism in medicine. Individual clinicians who treat PsA want the best for all of their patients but may wonder what they can do to narrow the treatment gaps that contribute to these troubling disparities in care.

Racial and Ethnic Differences in PsA Prevalence

Little research has been conducted on the prevalence of PsA among different racial/ethnic groups, as the majority of epidemiologic studies have been conducted primarily among Whites.⁶ For example, in a recent population-based study of PsA in Olmstead County, MN, only 2% of the 164 individuals who developed PsA from 2000 to 2017 were Black and 5% were Hispanic, limiting the amount of information available for these groups.¹¹

Instead, much of what we know about PsA prevalence in minority groups must be extrapolated from studies of psoriasis. Estimates of the prevalence of PsA among patients with psoriasis vary from 8% to 30%,¹²⁻¹⁴ and it is well established that most patients with PsA develop psoriasis first.^{15,16} According to data from the National Health and Nutrition Examination Survey, the prevalence of psoriasis is higher among Whites (4%) than Blacks (2%) or Hispanics (2%).¹⁷ A recent analysis of a large health records database painted a similar picture: the prevalence of psoriasis was 2% in Whites, 0.5% in Blacks, and 1% in Hispanics/Latinos.¹⁸

The relative prevalence of PsA in different groups with diagnosed psoriasis appears to be similar. Among patients with psoriasis, one study found that PsA is less common in Blacks (30%) than Whites (65%).⁵ Another study found that the prevalence of severe-to-very-severe psoriasis (criteria included severe or mutilating arthritis) varied slightly by race; 40% of White patients and 36% of Black patients with psoriasis had severe-to-very-severe psoriasis.¹⁹ The highest prevalence of severe-to-very-severe psoriasis was in Hispanic patients (52%) and the lowest in patients of Middle Eastern descent (25%), though the authors of this study cautioned that the numbers of participants in the Black and Middle Eastern groups were too small to be reliable. A high prevalence of PsA in Latino patients is supported by results from a recent study that found that Latinos with psoriasis were more

likely to use biologics than non-Latinos; the authors hypothesized that one explanation for this finding could be a higher prevalence of PsA in Latino patients.²⁰

In short, existing data suggest that certain minority groups, such as Hispanics/Latinos, are at higher risk for PsA than Whites, whereas others, such as Blacks, are at lower risk. The frequency of genetic variants linked to PsA may play a role in disparities in disease prevalence, manifestations, and outcomes in different groups; this possibility, however, remains poorly understood.^{4,21} Low PsA prevalence in Blacks may also reflect underdiagnosis,⁴ possibly resulting from limited access to care or lower awareness of the condition.²² Much more research on the basic epidemiology of PsA in different race/ethnicity groups needs to be done.

Racial and Ethnic Differences in PsA Severity and Disease Manifestations

Although data suggest that patients from some minority groups are less likely to develop PsA than Whites, they also indicate that those who do develop the condition will experience more severe disease. For example, although PsA is less common among Black patients with psoriasis than White patients, Black patients experience more severe skin involvement, greater psychological impact, and more impaired quality of life.^{4,5} In a study conducted by the National Psoriasis Foundation that focused on the psychosocial impact of psoriasis, 72% of minority respondents reported negative impacts on their quality of life vs. only 54% of White respondents.⁴ Specifically, respondents who reported negative impact on their quality of life described feelings of self-consciousness, embarrassment, anger, frustration, and helplessness.

PsA manifestations also differ among race/ethnic groups. Nearly all patients with PsA also experience psoriasis.²³ Dermatologists report that, in Black patients, psoriasis is more likely to present with dyspigmentation, which can be as distressing as psoriasis itself. In addition, dermatologists report that Black patients are less likely than White patients to develop erythema, though this belief may reflect the challenges that many clinicians experience detecting erythema on darker skin. Instead of being pink or red, as it appears on lighter skin, erythema in patients of color may appear dark brown or violet, confusing healthcare providers who are not familiar with its manifestations on all skin tones.⁴

Underdiagnosis and Undertreatment of PsA in People of Color

For a variety of reasons, people of color with PsA are more likely to be underdiagnosed, undertreated, or inappropriately treated than people with lighter skin.

First, clinicians may have difficulty diagnosing PsA in patients of color. This difficulty may have serious consequences for patient health, as early and effective treatment is key to improving long-term PsA outcomes,²⁴ and diagnostic delays of just 6-12 months are associated with joint damage and worse functional outcomes.^{25,26} Evidence indicates that many healthcare providers find diagnosing psoriasis, which often precedes a diagnosis of PsA, more challenging in patients with darker skin. For example, without a biopsy, it can be difficult to distinguish between psoriasis and lichen planus, sarcoidosis, and cutaneous lupus on dark skin.⁴ In addition, textbook images of what psoriasis looks like often feature fair skin, so some clinicians may not be familiar with how it appears in people of color.²⁷ Indeed, in an analysis of over 1,000 photos of rheumatic disease manifestations from medical image libraries and textbooks, only 13% of photos featured patients with dark skin.²⁸ This percentage is much lower than the percentage of people of color in the United States (21%). Not surprisingly, in a study in which dermatologists were presented with a description and photos of patients with severe psoriasis, respondents were much less likely to be confident in diagnosing psoriasis when the patient was Black instead of White.²⁹ Black patients experience a shorter period between psoriasis diagnosis and PsA diagnosis than White patients, a finding which can probably be explained by Black patients being diagnosed with psoriasis later in the course of disease.⁵

Patients of color with PsA also appear to be undertreated. Black patients with psoriasis/PsA are significantly less likely to use biologics than White patients.^{5,30} The difference in biologic use can be stark: One study found that whereas 46% of White patients with psoriasis/PsA receive biologic therapy, only 13% of Black patients do.⁵ Another study found that Black patients with psoriasis/PsA are 70% less likely to receive biologics than White patients.³¹ Even more concerning, among Black patients with PsA, both biologic and non-biologic disease-modifying antirheumatic drugs (DMARDs) are infrequently prescribed,⁵ even though DMARDs are the only medications that can actually prevent joint damage. American College of Rheumatology (ACR)/National Psoriasis Foundation guidelines recommend DMARD-based treatment for all patients with PsA and suggest starting most patients on a TNF inhibitor.²⁴ Thus, many patients of color with PsA do not appear to be receiving guideline-concordant therapy.

Multiple possible explanations exist for the low rate of systemic PsA therapy use among patients of color. One explanation involves socioeconomic factors. Biologic medications are expensive, infusions may require time off work, and coverage depends on a patient's insurance plan. In a recent survey of more than 3,000 patients with PsA, nearly one-third reported barriers to accessing treatment, most commonly due to lack of insurance coverage and high out-of-pocket expenses.³² Consistent with these data, a study of Latinos with psoriasis found that those with private insurance were more likely to use biologics than those with public insurance.²⁰ Patients of color tend to be especially vulnerable to financial

barriers to medical treatment, as race/ethnicity and socioeconomic status are intertwined.³³ Thus, financial barriers may help explain why non-Hispanic patients with psoriasis who belong to minority groups report fewer healthcare visits per year and are less likely to have seen a dermatologist for their psoriasis than White patients.³⁴ Even so, health disparities between racial/ethnic groups remain after controlling for socioeconomic differences, indicating that financial barriers do not offer a complete explanation for these differences.⁷

A second explanation for the low rates of systemic PsA therapy use among patients of color involves knowledge gaps among clinicians who treat this condition. In the study described previously in which providers were presented with descriptions and photos of patients with psoriasis, lack of confidence in diagnosing patients was associated with a lower likelihood of recommending appropriate treatment for severe psoriasis.²⁹ Patients of color may be especially vulnerable to undertreatment by clinicians who are unfamiliar with best practices for diagnosing and treating PsA.

Healthcare disparities may also result from differences in treatment preferences among different racial/ethnic groups.⁷ In support of this explanation, one study

found that treatment preferences among patients with rheumatoid arthritis differed by race.³⁵ Whereas Black patients weighed the theoretical risk of cancer associated with treatment most heavily, White patients weighed the likelihood of remission and halting radiographic progression most heavily (see Table 1). Moreover, 52% of Black participants in this study were classified as being risk averse vs. only 12% of White participants. Similar differences in the perception of available treatments between racial/ethnic groups may exist for PsA. For example, in a study of patient perceptions of psoriasis therapies, both Black and White patients who had never tried biologics associated them with terms such as “apprehension,” “side effects,” and “immune suppression.”³⁶ However, only Black patients also associated biologics with the terms “unfamiliar” and “dislike needles.” Of note, a recent study found that racial/ethnic minorities are underrepresented in direct-to-consumer advertisements for psoriasis and eczema, mirroring racial disparities in treatment with biologics.³⁷ If consumers are more likely to pay attention to and be influenced by sources they perceive as similar to themselves, then a lack of representation in PsA treatment commercials could contribute to the low rates of familiarity and comfort with biologics in some groups.

Table 1 Relative Importance of Treatment Characteristics by Race³⁵

In a study of patients with rheumatoid arthritis, 67 Black and 69 White respondents were given 100 points and asked to assign them to 10 treatment characteristics, weighting each choice based on how important they believed each characteristic was. Black patients were significantly more likely to weigh route of administration and various risks associated with a treatment heavily, whereas White patients were significantly more likely to weigh treatment effectiveness heavily.

Note: the points for each group do not add up to 100, as they represent group median (not mean) values.

Median relative importance (points)

Treatment characteristic	Black	White	P
Likelihood of remission	11.0	15.7	<0.0001
Likelihood of symptoms improving	9.9	14.5	<0.0001
Likelihood of arresting radiographic progression	9.8	15.4	<0.0001
Route of administration	10.2	7.8	0.02
Risk of injection reaction	8.6	6.3	0.03
Risk of nausea	7.4	5.9	0.3
Risk of lung injury	10.5	9.3	0.3
Risk of tuberculosis	8.6	4.4	<0.0001
Risk of neurologic disease	8.6	6.3	0.002
Risk of cancer	13.6	10.3	0.008

Importantly, once PsA treatments such as biologics are prescribed, there is no evidence that adherence varies according to race/ethnicity. In an analysis of insurance claims, no significant differences in adherence to systemic treatment for PsA were found among different racial groups.³⁸

Additional Challenges in Accessing PsA Care for Patients of Color

Rheumatology specialists typically consider reducing joint pain one of their top treatment goals for patients with PsA.³⁹ In general, however, when seeking help for pain, patients of color experience shorter office visits, fewer pain medication prescriptions at lower doses, and longer wait times to receive pain medication than White patients do.^{40,41} Black patients experience a greater number of disparities with regard to pain management than any other racial/ethnic group, and those disparities are also larger than other groups.⁴² Racial bias on the part of healthcare providers is seen as one potential cause of this healthcare disparity. In one study that asked more than 400 physician residents and fellows to evaluate virtual patients seeking care for pain, roughly 50% demonstrated a statistically reliable treatment bias against people of color.⁴³ Patients from minority groups may also be reluctant to report pain, even when it is severe.⁴⁰ Research shows that Black patients tend to minimize pain; some may believe that talking about pain is likely to increase its intensity and power in their lives.⁴⁰

Language can also represent a barrier to effective PsA treatment. Census data indicate that more than one-fifth of U.S. residents ages 5 years and older speak a language other than English at home.⁴⁴ Many of these individuals have limited English proficiency, making communicating with healthcare providers about symptoms, diagnosis, and treatment for any medical condition challenging. As a result, patients with limited English proficiency perceive their interactions with healthcare providers as lower quality than patients who primarily speak English.⁴⁵

Providing Culturally Competent PsA Care

Rheumatology specialists can implement a variety of strategies to help remove the barriers that cause health disparities among racial/ethnic groups, including the following (see Figure 2):

1. Take special care to build rapport with patients from minority groups. Giving patients time to discuss how they are doing and what they are feeling is one good way to ensure that patients feel comfortable reporting their symptoms.⁴⁰ Healthcare providers should also make it clear that reporting PsA-related pain will not be perceived as complaining and will not inconvenience the healthcare team. It should alternately be emphasized that when patients communicate

Figure 2

Nine Strategies for Building a Culturally Competent Rheumatology Practice⁵⁷

- Provide interpreter services
- Recruit and retain staff from minority groups
- Provide staff members with cultural competency training
- When applicable, coordinate with traditional/folk healers to maximize treatment efficacy and minimize complications due to incompatible treatments
- Build relationships with community health workers, who can link vulnerable patients to rheumatology care
- Engage in culturally competent health promotion, such as encouraging early PsA detection and treatment
- Include family and/or community members in care plans when appropriate and consistent with a patient's wishes
- Encourage staff to immerse themselves in the cultures from which their patients come
- Consider which accommodations could improve access to care for patients of color, including making changes to hours of operation and membership in insurance networks

openly and honestly about their pain, it gives the healthcare team important information it can use to guide treatment.⁴⁰ Clinicians should be aware that some patients of color may be more comfortable endorsing words such as “hurt,” “sore,” or “discomfort,” as they may reserve the word “pain” to refer to only the most severe pain.⁴⁰ Healthcare providers should also pay careful attention to a patient's body language and tone of voice when they are discussing pain, as these features may convey important information about the severity of a patient's PsA symptoms.⁴⁰

2. Make sure that patients with PsA are appropriately informed about all of their treatment options, providing information about each therapy's efficacy, safety, side effects, and cost. Inadequate or inaccurate information about treatment options can be a source of health disparities in rheumatic disease.³⁶ Improving the provision of information about biologics in particular may be important for reducing PsA health disparities, as

Black patients are less likely to use biologics and more likely to be unfamiliar with this type of medication.³⁶

3. Become familiar with concerns common among patients of color. For example, dyspigmentation is a major concern for many patients of color with psoriasis.⁴ Therefore, it is important for clinicians to explain that phototherapy may increase pigmentation and that postinflammatory hyperpigmentation can result from phototherapy-associated burns. In addition, clinicians should convey that the hyperpigmented lesions that develop after phototherapy are usually not permanent, do not represent active psoriasis, and should not be treated with topical steroids.⁴⁶
4. When developing a PsA treatment plan for a person of color, collaborate with the patient to determine how appropriate various therapy options are for them. For a Black woman who cannot wash her hair daily, for example, a treatment regimen for scalp psoriasis that requires daily hair washing with a prescription shampoo would not be appropriate.⁴ A more suitable treatment might include weekly hair washing with a medicated shampoo and daily application of a topical corticosteroid that will not harm her hair or interfere with her styling routine.
5. Offer eligible patients of color the opportunity to enroll in clinical trials. The lack of diversity in clinical trials is a major problem throughout medicine as it limits knowledge regarding the effectiveness and safety of medicines in different racial/ethnic groups. Indeed, much of what we know about PsA is based on studies that enroll a vast majority of White participants.²¹ Clinical trials for PsA therapy are gradually becoming more diverse, but they are still heavily weighted toward White participants. For example, in recent trials for PsA therapies, 87% of participants were White, down from 97% in older trials.⁴⁷ By making it a point to let patients of color know which trials they are eligible for, clinicians can help strengthen the evidence base that informs care for all patients. In addition, some patients eligible for clinical trials may appreciate the cost savings of receiving free treatment.

Creating Culturally Competent Rheumatology Practices

Although it is important for rheumatology providers to take action to provide more culturally competent care, in order to truly address healthcare disparities, changes will have to take place at the practice level. Creating a culturally safe medical home for all patients requires a systemic approach rather than one that relies on individual practitioners to create change.⁴⁸ This may sound overwhelming, but even smaller practices can take important steps to improve cultural competency and thus care for patients in underserved groups. Here are some suggested steps for today's rheumatology practices:

1. Make sure that all staff are aware of the deleterious impact that healthcare disparities have on patients.⁴⁹ Becoming aware of the scope of this problem is an important first step in targeting healthcare disparities. A 2008 survey of nearly 900 physicians found the following:⁵⁰
 - Only 55% of respondents agreed or strongly agreed that “Across the United States, minority patients generally receive lower quality care than white patients” (100% of health disparity experts agreed or strongly agreed with this statement)
 - Only 51% agreed or strongly agreed that “It is important for physicians to devote extra time to the health needs of their minority patients”
 - Only 50% agreed or strongly agreed that “I often think about what I can do to interact more effectively with my minority patients”
 - Only 75% agreed or strongly agreed that “I am in a position to make a difference in the quality of health care that minority patients receive”

These results demonstrate a lack of awareness of both the existence of healthcare disparities and the importance of healthcare providers in correcting these disparities. Awareness of healthcare disparities has grown in recent years, but many healthcare workers are still likely to lack important information about this problem, as well as their own ability to help fix it.

2. Make sure that every rheumatology care provider on staff feels comfortable diagnosing and treating PsA in patients of color. Setting up practice-wide educational sessions to discuss topics such as how psoriasis manifests on darker skin and how to ensure adequate pain management in patients of color may be helpful.
3. Review how well the practice is equipped to serve patients with limited English proficiency. For practices that are part of larger systems, medical interpreters may be available. For practices within these health systems, reviewing the optimal use of interpreters with staff may be useful. In smaller practices, if a staff member can speak another language fluently, it may make sense to help them get certification for their language skills and receive training as a medical interpreter.⁵¹ In fact, if many of a practice's patients speak a certain language, it may make sense to consider fluency in this language an asset when hiring new staff. Locating or creating patient education materials on PsA in languages commonly spoken by patients within a specific practice can also be an important technique for supporting patients with limited English proficiency. For example, MedlinePlus, the U.S. National Library of Medicine's website for the general public, offers patient-oriented information about PsA in Spanish as well as English.

When it comes to communicating with patients who have limited English proficiency, providers should be aware of several common practices that may impede the provision of quality care. Using common translation apps may put a practice at legal risk, and use of these apps for treatment purposes may also not be HIPAA compliant.⁵¹ In addition, clinicians should not rely on family members, especially those younger than 18 years of age, to translate for patients. Family members may not feel comfortable conveying sensitive but crucial information relevant to treatment, they often lack the medical vocabulary necessary for accurate translation, and using family members in this way may violate patient confidentiality.⁵¹ Thus, relying on professional translators is the best option.

4. Because many medications used to treat PsA are expensive, practices can explore options for improving access to DMARDs, regardless of a patient's insurance status or ability to pay.⁶ It may be possible to connect patients without insurance to state-subsidized insurance programs or Medicaid. Similarly, it may be possible to link patients who have trouble affording their copays, or whose insurance does not cover these medications, to manufacturers' patient assistance programs or state- or foundation-run programs designed to help patients afford medicines. To make connecting patients to assistance programs a routine part of care, practices can identify all relevant assistance programs, make information about the programs easily accessible to everyone who provides PsA care in the practice, and make sure that every healthcare provider in the practice discusses strategies for affording treatment with every patient who arrives for a visit.
5. Institute standardized protocols to ensure that important services are performed for each patient with PsA.⁴⁹ Such protocols may specify, for example, that each patient be informed about the full range of appropriate treatment options. To ensure that all patients receive the same high-quality information about various therapies—including treatment pros and cons—it may be helpful to create educational materials that patients can take home with them.⁴⁹ Protocols may also dictate that all PsA patients who are starting biologics be screened for latent tuberculosis as recommended by ACR/National Quality Forum, and receive the 13-valent pneumococcal conjugate vaccine, as recommended by the Advisory Committee on Immunization Practices for individuals ≥ 18 years old with an immunocompromising condition.⁴⁹ Finally, protocols might specify that each female patient with PsA who is of reproductive age receive reproductive health counseling, as many PsA medications are potentially teratogenic.⁴⁹ One technique to simplify enacting such protocols is to categorize patients in need of certain services ahead of time so that the relevant offerings can be targeted to them.⁴⁹
6. Measure the practice's progress toward reducing health disparities.⁷ Relevant metrics might include the percentage of patients of color with PsA who are

Figure 3

Helpful resources for reducing disparities in PsA care

Liberation in the Exam Room Toolkit

<http://www.ihl.org/resources/Pages/Tools/Liberation-in-the-Exam-Room-Racial-Justice-Equity-in-Health-Care.aspx>

A document designed to guide discussions of racial justice and equity in healthcare within the healthcare team. Includes many helpful resources and suggestions for improving healthcare for patients of color.

VisualDx

<https://www.visualdx.com/>

Website and app with medical images to help educate healthcare providers about how PsA and other rheumatologic conditions manifest on darker skin

Project Impact

<https://www.visualdx.com/projectimpact/>

A website through which users can contribute images of PsA and other conditions in patients of color, access key research on health disparities, and find helpful resources for recognizing rheumatologic conditions in darker skin

ACR's Diversity, Equity, and Inclusion Website

<https://www.acrwebsite.org/web/about/diversity-equity-inclusiveness>

Features ACR's Statement on Racism and a description of the organization's future plans to alleviate systemic racism in the field

(1) receiving systemic therapies, (2) have achieved their treatment targets (the European Alliance of Associations for Rheumatology's PsA treatment guidelines recommend using remission, or alternatively,

low disease activity as targets⁵²), or (3) have received recommended services of the type described in the previous paragraph. By measuring improvement over time in metrics such as these, practices can tell whether what they are doing is working—and adjust their processes as needed. When possible, practices

can link improvement in care to financial incentives for providers to help drive change.⁴⁹ Tracking the diversity of a practice's staff may also be helpful,⁴⁸ as clinicians of color may be more familiar with PsA-related issues, including barriers to effective diagnosis and treatment, among patients of color.²⁷

Conclusion

Increasingly, the field of rheumatology is turning its attention to reducing healthcare disparities. For example, ACR recently launched a Diversity, Equity, and Inclusion Task Force. Recent discussions involving this task force have covered the impact of race and ethnicity biases on American Board Of Internal Medicine (ABIM) test questions, plans to develop ABIM test questions related to health equity, and making diversity, equity, and inclusion part of the curriculum that prepares residents to become board-certified physicians.⁵³ In addition, the American Academy of Dermatology is working on improving its image library to better prepare clinicians to recognize specific conditions such as psoriasis in patients with darker skin.⁵⁴ These systems-level efforts will be essential toward moving the needle on health equity. At the same time, however, every rheumatology provider has an important role to play in ensuring that all patients with PsA receive quality care. By taking advantage of resources already available to help reduce healthcare disparities (see Figure 3) and working to implement the strategies described in this article, both individual clinicians and entire rheumatology practices can do their part to reduce healthcare disparities.



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Experimenting with a Different Approach

by Carrie Beach, BSN, RN-BC



Treating rheumatology patients can be tough. I can't tell you how many times I have told patients that a lot of what we do to get their disease under control is "trial and error," which is never what they want to hear. They want us to be mechanics, to get under the hood, figure out what is wrong, and provide a solution. Unfortunately, the body is not an automobile, and we can't use our toolbox to root around inside to see exactly what is happening. So while I always portray confidence that we will find the right treatment to get our patients feeling better, I understand their frustration in being made to feel at times like guinea pigs.

Louise, a 77-year-old Black female, came to us after being treated for significant rheumatoid arthritis (RA) for more than three decades. Louise was unsatisfied with the care being provided by her rheumatologist and the treatment plan he had prescribed for her, so she came to our practice hoping for a different perspective. Her disease activity had been well controlled with weekly etanercept for many years, but at our initial meeting, she told me that she had stopped taking it about 3 months ago because it was no longer controlling her joint pain and swelling. I asked Louise about other previous medications, and she told me that she thought she had been on methotrexate

(MTX) but had stopped taking it for a reason she couldn't remember. Consequently, after taking appropriate labs, we started Louise on another trial of oral MTX.

At her initial 4-week follow-up, Louise reported some improvement in symptoms, but she was having some side effects to MTX and, with the damage to her hands, was hesitant in her abilities to draw the injectable version of MTX without help. That led us to try leflunomide 20 mg daily. Louise tolerated that drug just fine but decided after a few months that it wasn't helping her symptoms, so she asked to be switched to something else. After reviewing some potential options with Louise, she said she thought she would do OK with an autoinjector, and since she had had previous success with etanercept, we switched her to another TNF inhibitor, adalimumab 40 mg every other week. Adalimumab worked for about a year before its effectiveness began to wane. That next led us to switch classes, going to injectable abatacept. Louise tried that for about 6 months without much improvement. Next, despite Louise's reticence with infusions, she agreed to try tocilizumab since her symptoms were becoming worse and more significantly affecting her quality of life.

Like I said, trial and error.



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Louise called me a few days after her initial tocilizumab infusion. She was upset and frustrated that she wasn't feeling any better, and actually told me her symptoms had gotten worse following the initial infusion. This is something I hear commonly from patients who don't understand that many of the biologics we use in rheumatology take time to work. I patiently explained to Louise that her initial response was totally normal and even expected, but that she should start to feel better after a few more injections. She agreed to keep trying with tocilizumab, but I could sense her hesitance over the phone.

A few days later, I got a voicemail from Louise's husband, Jack. He was clearly upset and asked that I call him back as soon as possible. I could tell this was going to be a challenging conversation, but I put on my big girl pants and saddled up. Jack was clearly unhappy with the course of his wife's treatment under our care and told me that he didn't understand why his wife wasn't feeling better. At this point, Louise had been our patient for approximately 2 years and had been on five different medications.

Jack told me that he didn't feel like our team was listening to his wife and considering her needs. He said that it seemed like we were just throwing whatever medications we wanted at her, even if they weren't in her best interests. Jack proceeded to explain to me that his brother was one of the Tuskegee airmen who had participated in the government's infamous and unethical syphilis trial, and he felt that now, we were treating his wife like she was a medical experiment against her consent. Furthermore, he said he had no trust in our team's ability to care for his wife.

Admittedly, this all threw me for a loop. We're all used to dealing with angry patients and even their spouses from time to time, but this was the first time I had been accused of running "an experiment" with a patient. I wanted to get a better perspective of Jack's mindset, so I let him talk for a while and

explain his viewpoint. I can honestly say that it was one of the most enlightening moments of my nursing career. While I've always known that building trust and rapport with patients and their families was essential, I never considered that some patients might feel like we are them as "an experiment." The good news is that I had a lengthy, open, and honest conversation with Jack about the steps we had taken in the treatment of his wife and why we had made the recommendations that we had along the way. I think I was able to get across to him that our goal was the same as his—to get Louise's disease under control so that she felt better.

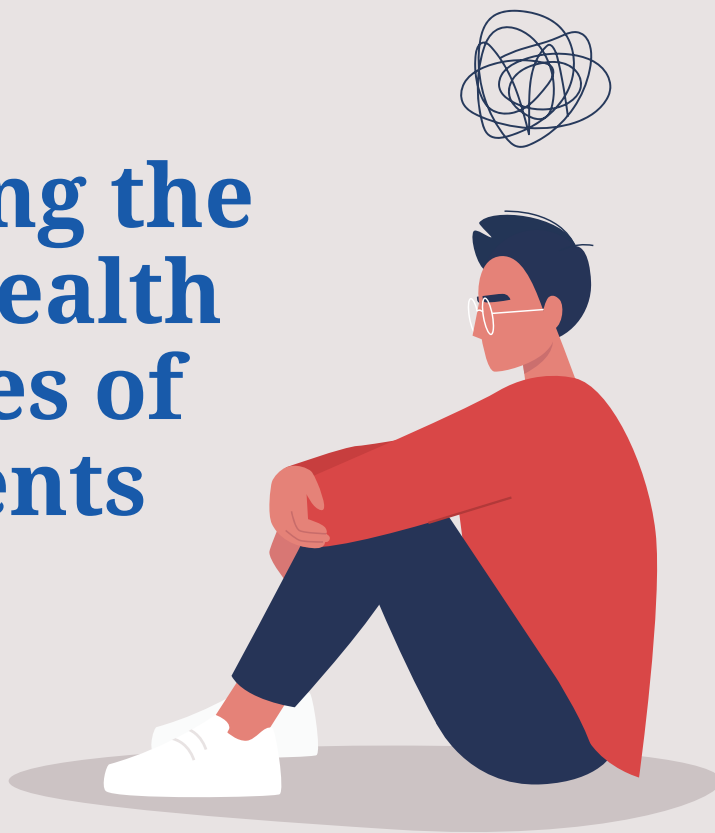
It's been close to 10 years since this conversation with Jack occurred, but I still remember it well, especially when I'm having a difficult time building a trusting relationship with a new patient. Louise was our patient for another 5 years before she passed away of a condition unrelated to her RA. I wouldn't say we ever really developed a close patient-provider bond, but I did try to engage her more in discussions about her treatment, current adjustments we might be able to make, and ways to improve her life on a day-to-day basis.

I've been in practice long enough that it's sometimes easy to go on autopilot when explaining how we typically will treat a common rheumatic disease such as RA and assume that the patient will simply go along with our suggested treatment plan. It's those times when I catch myself before I go too far and remember that every one of our patients comes from a different background with a unique history and perception of healthcare. Some will require a more nuanced approach that tests our listening skills and ability to adapt to their belief system. Patient communication is not a one-size-fits-all approach. It's something we all need to consider when we're dealing with a patient with whom we don't seem to be connecting very well—what can we do to be a better provider for this patient today and in the future?



Addressing the Mental Health Challenges of Our Patients

by Joni Fontenot, RN



Of all the disparities in the healthcare system our patients face, there is one that does not discriminate. It has nothing to do with finances, access to care, or transportation. I see it day in and day out with my infusion patients, and its onset can rarely be predicted or prevented.

Depression.

We have all heard about depression and may have seen it in people we know. Maybe some of you have personal experience with it. As a specialty centered on the physical well-being of our patients, rheumatology providers are not specifically trained in the management of depression, but it sure is something that always needs to be on our radar screens.

Through my time as a rheumatology nurse, I have learned that depression doesn't simply present as "I am sad." Instead, there are two primary scenarios that I have become attuned to.

SCENARIO 1:

The Patient Left Swaying in the Wind

This is the patient who is going along in life happy and healthy until one day they have this

weird combination of symptoms that pop up out of nowhere that can't be attributed to any one thing. They go to their doctor, typically a primary care provider (PCP), and are told that they probably have a viral illness that is going to be short lived. All they need to do is take "Drug XYZ" for a few days or weeks and everything will get better.

A month later, nothing is better (and is often worse), and there is still no answer. Instead of a more thorough workup and referral, they get sent home and told, "It's just a function of getting older." And so the patient suffers for months, sometimes years, not knowing exactly what is going on, but knowing all too well that something isn't right with their body. They have symptoms they can't explain, pain and stiffness in their hands and wrists that don't seem to have any cause. Maybe they develop an unsightly rash on their skin that triggers weird looks from people at the beach. Family members grow tired of the patient's complaints and keep telling them, "You look fine. There is nothing wrong with you. Deal with it."

This is the patient who begins to shut themselves off from society, stops doing things they enjoy, and avoids being around the people they love. Depression sets in heavy and hard. They begin to lose hope that things will ever get



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“While acknowledging their feelings and thoughts, I also do what I can to encourage them to take things one day at a time and rebuild themselves little by little.”

better until one day they finally reach the world of rheumatology. This is the patient who comes to us with a hangdog look on their face who just doesn't seem to have any energy.

SCENARIO 2:

The Discouraged Patient Who Has Given Up Hope

This is the patient who is fortunate enough to have a PCP attuned to the possibility of an inflammatory condition. The PCP questions their initial diagnosis when things don't immediately improve and orders lab tests to assess the patient's C-reactive protein levels, erythrocyte sedimentation rate, and other relevant values. Those results then trigger a referral to either rheumatology or dermatology.

While this patient gets fast tracked to a specialist and forgoes the lengthy diagnostic period, they still face a series of challenges. They expect instant results from medications and don't understand why their prescription doesn't dull the pain immediately. Maybe their first and second medications don't work at all, and they begin to wonder if there is anything that can truly help. This leads to a questioning of their provider and medication noncompliance. Which puts them back at square one.

As an infusion nurse, I see lots of patients like this. We don't often see patients until they have tried and failed to respond to multiple oral and/or subcutaneous medications. By the time they get to the infusion center, they think this will simply be another waste of time and are completely closed off. I see the despair on their faces and have to work really hard to try to get through to them.

Seeing Through the Haze of Depression

While I do see some patients who are seeing a psychiatrist and being treated with an antidepressant, there are many who show signs of depression but have never been formally diagnosed. Regardless of which group the patient falls into, my approach is the same—I begin by sitting down with them and explaining the infusion process from start to finish, telling them about the medication they are receiving and what we think/hope it's going to do. I also review some of the potential side effects so as not to sugarcoat things too much and describe what they should expect from the infusion process in general.

I find it important to try to gauge patients' state of mind when I first meet them, to assess where they are in the disease process and get a sense of any concerns or barriers to care that they face. I listen wholeheartedly and empathetically. I literally tell them I am going to be “all in your business,” which makes them laugh but expresses how serious I am about helping them get better. While acknowledging their feelings and thoughts, I also do what I can to encourage them to take things one day at a time and rebuild themselves little by little. There are no massive strides to be made in the morning with a chronic rheumatic disease.

In the end, what I am trying to do is prevent my patients from going into an emotional dark hole and, if they are already there, try to pull them out by letting them that it's OK to feel the way they do. I am proud that I have many patients who specifically ask for me to take care of them on their infusion days and some who tell me things that they admit they don't feel comfortable sharing with their provider. This always puts me in a tricky spot—I don't want

to betray my patients, but I also know it's ultimately to their benefit to speak openly with their provider.

For some patients, we are the only support system they have. I had one patient recently who came to us with a terrible rash over nearly her entire body. A few months after I met her, she brought me a gift, which surprised me. When I asked her what I had done to deserve it, she told me that I was one of the very few people who treated her like a human being and wasn't scared off by her rash. I told her that her rash had nothing to do with the beautiful person she was and that she shouldn't let other peoples' opinions derail her life. After I left work that day, I cried. I cried because of what this woman has to go through on a daily basis because of something on her skin. I cried because I knew how cruelly she is treated by others and because I wanted her to be proud of the beautiful person she was inside and out.

One last point—don't forget our role as mandated reporters. This means that any time one of our patients

expresses an intent to harm themselves or someone else, we must report this up the chain of command, typically to their rheumatologist. That individual can then determine if the patient needs to be sent to the ER for evaluation or, in Louisiana where I practice, execute a Physician's Emergency Certificate to detain the patient for 72 hours. Luckily, I have not been forced to go down this road with any of my infusion patients, but this happened frequently in my previous role as a post-op and ER nurse. Your patient may never forgive you if you betray their confidence to their provider, but emergency situations leave us no choice.

So many of us make a profound impact in the lives of the patients that we care for. Having simple, honest conversations can open a door of trust and help develop a rapport that establishes yourself as the guiding light that instills hope for your patients who are looking for something, anything, to hold on to. Especially in these trying times, our patients need us more than ever.



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Lost in Translation

by April Johnson, MSN, APRN, CNP



AUTHOR PROFILE:

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Remember the game “Whisper Down the Lane?” Basically, the game would start with the person at the head of the line, who would think of a sentence, something like “Sally went to the store and bought strawberries, pork chops, and milk.” They would then whisper that sentence to the next person in line, who would whisper it to the next person, and so on. The person at the end of line would then be asked to recite the sentence as they had heard it. Usually, it would come out as something like, “Stan went sailing, got seasick, and fell asleep.” The point of the exercise was to show how words get garbled as more and more individuals are inserted between the first and last people in line.

Now in healthcare, we never want to be stuck playing “Whisper Down the Lane” with our patients. We want them to hear about their disease and options for treatment directly from us without anyone else getting in the way. But that’s not always possible. It may be due to technology barriers (who hasn’t been frustrated by a poor Internet connection during a recent telemedicine visit?), language barriers, or something else entirely. And those kinks in the communication chain can really have a detrimental impact on patient care.

I recently had a patient who drove home this lesson for me.

Hosana, a 44-year-old undocumented immigrant who first came to the United States in 2003, was waiting patiently with her daughter for a follow-up appointment at our practice when I met her for the first time 2 years ago. I knew that Hosana was often anxious at these visits because of her limited command of the English language (she is a native Spanish speaker). Her daughter, Lilliana, typically accompanied her to each appointment to help broker communication with our team.

Hosana had been a patient at our practice for approximately 3 years before I met her and, during that time, her psoriatic arthritis (PsA) slowly but surely continued to progress. Through her daughter, I learned that Hosana never felt she was able to properly communicate her level of pain and discomfort to her previous providers, but that she had simply grown accustomed to living in pain. Hosana didn’t seem to understand her disease very well and couldn’t quite grasp the purpose of the various medications she had been prescribed over the years. Hosana owned a very busy and successful housecleaning business, but she told me that she was having more and more difficulty keeping up with work due to the pain in her hands and wrists. In addition, her psoriasis had become quite itchy and bothersome. Hosana’s planned visit to Mexico to see her family was temporarily put on hold.

“Through her daughter, I learned that Hosana never felt she was able to properly communicate her level of pain and discomfort to her previous providers, but that she had simply grown accustomed to living in pain.”

At our initial visit, Hosana (through Lilliana) told me that her sulfasalazine had pretty much stopped working entirely. She had initially been given methotrexate by one of our team’s rheumatologists, but the co-pay was too high, and Hosana was forced to stretch the 30-day supply to 60 days. Not surprisingly, that blunted the impact of the medication on Hosana’s pain. I asked Hosana what other options she had been offered at that time, but she said she couldn’t specifically remember, only that it was a drug that “could cause cancer.”

While I performed a comprehensive physical exam, I asked some more questions about Hosana’s current standard of living and day-to-day activities. Eventually, she began to cry, saying that she was in constant pain and needed something better than sulfasalazine. Knowing that Hosana had been easily confused during previous conversations with other providers, I carefully went through the various options we could offer her, and it appeared that both she and Lilliana understood what I was telling them. Their first response was not unexpected—Hosana feared taking biologics because of the risk of developing cancer. This is something we hear a lot, especially from minority populations, and it can be a difficult barrier to overcome no matter how tenuous the link between biologic therapies and cancer. I spent some time reviewing the various classes of biologic therapies we have in our arsenal to treat PsA, the way they work, and common/uncommon complications related to each class. I also noticed in Hosana’s notes that one of our staff rheumatologists had started a

prior authorization for etanercept approximately a year ago but that it had never been completed. When I mentioned this to her, Hosana and her daughter had a brief conversation in Spanish before her daughter told me that Hosana was now willing to give etanercept a try. A new prior authorization form was initiated, and etanercept was approved a week later.

I instructed Hosana to schedule a follow-up appointment in 3 months to gauge her response to the biologic. Due to COVID-19 considerations, the appointment was switched from an in-person to a telemedicine visit. Lilliana again joined us to help as an interpreter. After some initial pleasantries, I asked Hosana how the etanercept was working and if she noticed any difference in her level of joint pain. She told me that, after leaving the office following her initial visit, she had time to further consider the risks and benefits of biologic therapy and decided against taking the etanercept. This was despite its being delivered to her home. Hosana then told me how her pain was only getting more severe, she was still unable to work, and was starting to suffer financially. She showed me a picture of her hands, which revealed multiple swollen joints with synovitis. She also had psoriasis on her nails. What, she asked me, could I suggest that might help?

While our patients do change their minds from time to time, and sometimes don’t even tell us when they do, these are still conversations that make us all want to stomp our feet and let off some steam. I knew how much Hosana was

suffering and that her options were limited if she truly wanted help with her pain. Clearly, she needed biologic therapy. I had done my best to overcome her hesitancy, but it was apparently not enough. Ultimately, providers have to realize that it is the patient's decision whether they want to start, continue, or stop any therapeutic regimen. We can only offer our advice and support.

So after taking a couple of deep breaths, I asked Hosana if she would be willing to come back into the office so I could more carefully examine her joints and further discuss a plan of attack that might be agreeable to both of us. Hosana agreed.

When Hosana came in a week later, I was prepared. I had arranged for a translator to be there for the duration of the visit—my hope was that this would make for a more efficient visit and would take the burden off of Lilliana. As detailed earlier in this issue of *Rheumatology Nurse Practice*, using a professional translator is generally preferred to relying on a family member who may not understand medical terminology and may unwittingly be passing incorrect information back and forth. Indeed, I came to learn that Lilliana misunderstood her mother's diagnosis as well as the mechanism by which etanercept works. It turns out that Lilliana didn't understand English as well as I had thought, and while she did her best during Hosana's visits, there was a major communication barrier. Lilliana said she didn't want to admit that she didn't understand some of the instructions I was providing because she thought that might force us to kick her mom out of our practice. She was incredibly grateful that we were able to provide a professional translator and further apologized for her role in her mother's decision not to start the etanercept. After another lengthy

discussion about the use of etanercept with our certified translator, Hosana and Lilliana both confirmed that they understood the treatment plan, the possible side effects and reactions she could potentially have to the injections, how to administer the injections, and what should prompt her to contact our office.

Hosana was back for her initial follow-up 3 months later. I made sure the same translator would be in the office with me (I wasn't going to make that mistake again!). Hosana and Lilliana both arrived with a smile on their face and were effusively grateful for the improvements in Hosana's pain and psoriasis. Her RAPID3 score was much improved, and Hosana had been able to resume her house cleaning business.

Hosana and Lilliana even told me that their recent experience in our practice had motivated them to learn English through a phone app, and I have noticed an improvement in their comprehension and fluency in the last 6 months. At our last visit, Hosana even told me how anxious she is to show off her language skills when she sees her family in Mexico later this year.

I'm glad that things have turned around for Hosana, but this case taught me an important educational lesson that I'm mindful of whenever I'm forced to overcome a communication issue with one of my patients. Never assume that what comes out of my mouth trickles down successfully to them when there are barriers in the way. There are steps we can fortunately take to overcome these barriers, but we must be proactive in our thinking and preparation to ensure we're not stuck playing Whisper Down the Lane with our patients and crossing our fingers that our message gets across.





THE PATIENT PERSPECTIVE



The Spoon Theory

by Callie Krakauskas

It's 6:30 a.m. and that pesky alarm clock is going off ... for the third time. I lay in bed for another 10 minutes, mentally logging which number I'm at on the standard 0-10 pain scale (0=no pain to 10=excruciating pain). Today feels like it's going to be a 4, which is pretty good for me after living with chronic pain—specifically rheumatoid arthritis (RA), fibromyalgia, and chronic migraine—for more than half of my 42 years.

Each morning after I wake up, I run through my seemingly never-ending mental to-do list. Do I need to go shopping? How many meetings do I have on my calendar? Can I work from home, or do I need to go into the office? And so on. I then think about what will be required to cross each item

off my list. Working from home during the COVID-19 pandemic has been a lifesaver for me and means I'll be more productive for one very important reason—I'll use up less spoons that I otherwise might have.

Before you scratch your head too much figuring out what I'm talking about, let me give a little background on the Spoon Theory. I was introduced to the concept in 2013, when its creator, Christine Miserandino, launched #SpoonieChat on her blog. The Spoon Theory is based on the idea that someone dealing with chronic illness has a limited amount of energy at the beginning of each day.¹ On her blog, Miserandino, who suffers from lupus, describes how she explained the Spoon Theory to her friend.



AUTHOR BIO

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“The idea of quantifying energy as ‘spoons’ has allowed me to convey to my friends and family what my day-to-day life is like.”

While sitting in a diner, she handed her friend 12 spoons, explaining that each spoon represents a unit of energy. She then asked her friend to list the typical activities she performs in a single day.

As her friend ran through her list of tasks for the day—showering, getting dressed, standing on a train, walking to the office, etc.—Miserandino took away one spoon for every task. By the time her friend got through half her day, she only had three spoons left. “Once the spoons are gone,” Miserandino told her, “so is your energy for the day. You can’t do anything more until tomorrow.”

Every task we perform, whether you have a chronic disease or not, takes up a certain amount of energy. The idea is that effortless tasks for most people—getting out of bed, taking a shower, getting dressed, making breakfast—are a little bit more complicated and take a lot more forethought for someone with a chronic disease. Depending on how we are feeling, it can be a struggle to simply get out of bed. Preserving your “spoons” is about rationing your energy, being mindful of each task, and understanding and weighing the consequences of going beyond your energy limit. It’s about balancing the day to day and understanding your limitations (see Table 1).

I’ve embraced the Spoon Theory as an easy and effective way to explain to others what living with chronic pain feels like. I have lost count of how many times I have heard, “But you look fine!” While I appreciate the sentiment, after 25+ years of struggling with RA and its myriad

secondary conditions, I’ve mastered the healthy facade and fake smiles. The idea of quantifying energy as “spoons” has allowed me to convey to my friends and family what my day-to-day life is like. They now understand what it means when I say, “I’m out of spoons.”

Let me give you an example of how this works. As I mentioned earlier, I woke up in the morning feeling like today was going to be a “4” on the pain scale, which is not too bad. Consequently, I assigned myself 14 spoons for the day. I then thought about everything I needed to get done—the laundry, the work assignments, the day-to-day minutiae that most of you probably don’t even think about—and calculated in my head how many spoons I would need to assign to each task. Most are one-spoon tasks, but a few can take two or three spoons. One of my biggest considerations each day comes at dinnertime. I am often exhausted by the time my workday is over, and cooking dinner is a task I usually dread. It can be a three or four spoon task. I know if I push to keep going after I’ve run out of spoons, I’ll end up paying for it tomorrow...and the next day... and the next. So takeout it is tonight!

I am extremely fortunate to have a supportive family who understand my situation. My partner often offers to lend me his spoons—while he says it somewhat in jest, what it tells me is that I can lean on him for support when I need it most. I know I won’t face any judgement if I need to crawl into bed at 5 p.m. because it’s already been a long day and I’m simply DONE.

Table 1 A Typical Day

Common Tasks	Number of Spoons
Making the bed	1
Morning stretches to loosen up the body	1
Preparing breakfast/lunch	1
Taking a shower	1
Washing and drying hair	2
Applying makeup and getting dressed	1-2
2-hour commute to work (roundtrip)	2
Grocery shopping	2
Laundry (per load)	1
Walking the dog	2-3
Working out	3-4
Preparing dinner at the end of the day	3-4
Standard 8-hour work day	5-6
Cleaning the house	6
Hosting a dinner party	5-6
Night out with friends	4

While it's important for individuals suffering with a chronic illness to be able to effectively communicate with their friends and loved ones, it's equally important for them to have an open and honest relationship with their team of healthcare providers. I have lost count of the number of rheumatologists I've seen over the years. If I don't feel comfortable in the first visit, or if I feel that they are not truly listening to me, I move on. As a patient with a longstanding chronic disease, no one knows my body and symptoms better than I do. When I talk to my provider, I need them to understand the limitations that my disease places upon me.

So the next time your patient smiles and says they're doing "Fine," think about what it takes for them to navigate life on a limited energy supply. Learn to look past the "Fine" to determine if they are truly the "3" that they say they are, or if their energy supplies are already depleted for the day and they just want to go home and crash. Using the Spoon Theory is a great way to foster open communication with your patients and really dig down into their day-to-day life. Are you their first spoon of the day or their last?



Reference

1. Miserandino C. The Spoon Theory. Available at butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/. Accessed September 15, 2021.



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