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The Corticosteroid Journey in PMR: Understanding the Patient Experience

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Dr Turck:
This is ReachMD, and I'm Dr Charles Turck. Today, we're going to shed light on the experience of patients diagnosed with polymyalgia rheumatica, or PMR for short. And joining us for this discussion are rheumatologists Dr Rodney Daniel, and Dr Grace Wright.

Welcome to you both.

Dr Daniel:
It's a pleasure to be here.

Dr Wright:
Thank you for having me.

Dr Turck:
Now, to begin, Dr Wright, would you give us some background on PMR?

Dr Wright:
Sure. So, of course, PMR is an inflammatory rheumatic condition characterized by pain and stiffness in the neck, shoulders, and hip girdles.[1,2] PMR tends to affect women more than men and generally affects individuals aged 50 and older[3] So, in adults over the age of 50, PMR is, in fact, the most common inflammatory rheumatic disease, surpassing even rheumatoid arthritis.[4] PMR can also involve other musculotendinous structures, including the hands, wrists, knees, elbows, and parts of the spine. Additional structures such ligaments, joint capsules, and bursae can also be affected by inflammation in PMR.[5]

Dr Turck:
And as a follow-up to that, Dr Wright, what causes PMR?

Dr Wright:
Well, the pathophysiology of PMR is not completely understood, but inflammation is known to play a key role in PMR pathogenesis.[1,6] Elevated serum levels of proinflammatory cytokines were observed in PMR patients when compared to patients with inactive PMR or healthy, age- and gender-matched individuals, and Interleukin-6, or IL-6, is believed to be a key driver of PMR pathogenesis, as its levels correlate with disease activity and recurrence.[6,7,8]

Dr Turck:
Thank you, Dr Wright, for that comprehensive overview. And turning to you now, Dr Daniel, let's switch gears and talk about the patients with PMR. How does the disease affect them?

Dr Daniel:
Absolutely. It's easy to focus on clinical symptoms, but the reality is that PMR has a profound impact on patients, and living with PMR can present significant challenges. For instance, the pain and stiffness often appear quickly, leaving patients confused. In fact, some

patients feel like they've suddenly aged, because activities that used to be simple have become increasingly difficult.[9,10]

Additionally, PMR pain can interfere with nighttime sleep, and these symptoms can lead to a reduction in quality of life for the affected individuals.[11] And so, it's very important to remember that PMR can result in significant physical impairment for patients. Approximately one-third of patients with PMR reported not regaining their pre-illness level of function, even after 2 years of standard treatment.[12]

Dr Turck:
Well, now that we have a better understanding of the physical implications, Dr Wright, what can you tell us about the *psychological* impacts that patients with PMR experience?

Dr Wright:
Of course, and that's a very important aspect of the disease. Limitations of PMR on daily activities often lead to helplessness, frustration, vulnerability, and a disrupted sense of self.[10] And so, it can lead to anxiety and depression, and as Dr Daniel previously mentioned, some patients can have significantly disrupted sleep.[10,12,13] All this can exacerbate symptoms of PMR, such as fatigue and inflammation, creating a cycle that's difficult to break.[11,12,14]

For example, a recent study showed that depression in PMR patients occurred 3 times more often compared to the general adult population.[13] Even after diagnosis, uncertainty about disease progression and adverse events associated with corticosteroid use may continue to weigh on the patient.[10] In addition to all of this, some patients have reported that trying to get a diagnosis was the biggest ordeal, so, in a way, receiving a PMR diagnosis can be a big relief.

Dr Turck:
Now, I'd like to dig a bit further into that idea. Dr Daniel, would you tell us more about the issues surrounding a PMR diagnosis?

Dr Daniel:
Of course. PMR is a clinical diagnosis that doesn't rely on specific biomarkers or confirmatory tests, so it isn't always straightforward,[15] and there are common conditions that mimic PMR, which can cause a misdiagnosis or a diagnostic delay.

As Dr Wright alluded to earlier, misdiagnosis can be a real problem for patients; in fact, studies show that it happens in up to 30 percent of cases.[16] The most common misdiagnoses are age-related aches or pains, fibromyalgia, and rheumatoid arthritis.[17] Diagnostic delays are common as well, with a recent study showing the median time to diagnosis is 3 months, which can be frustrating for patients.

Dr Turck:
So then, what are the first steps for a patient after receiving a PMR diagnosis, Dr Daniel?

Dr Daniel:
Once PMR is diagnosed, the current recommendation from the European League Against Rheumatism, or EULAR for short, and the American College of Rheumatology, more commonly known as ACR, is to prescribe a daily dose of 12.5 milligrams to 25 milligrams of prednisone, which classically results in an improvement of symptoms within the first few days.[3,18]

However, the challenge then becomes figuring out how to help patients taper off the steroids, all while keeping their PMR symptoms under control.

Dr Turck:
So, Dr Wright, when you're talking to patients with PMR, how do you explain the treatment approach and options to them?

Dr Wright:
Well, I first tell patients that the primary therapeutic objective is to achieve sustained, treatment-free remission of their symptoms. I explain that corticosteroids are utilized as a first-line therapy for the treatment of PMR, and a rapid response to corticosteroid treatment, typically within 1 week, is an important component of PMR diagnosis. In fact, the EULAR/ACR guidelines indicate that clinical improvement should be observed after 2 weeks of corticosteroid treatment, and by 4 weeks, almost a complete response can be expected.[18] Then I inform them that after 4 weeks, a tapering process can be started, with the aim of gradually reducing the dose until total discontinuation.[18]

Dr Turck:
Now, I understand that's the ideal tapering process time frame, but Dr Daniel, is that what most patients experience?

Dr Daniel:
Many PMR patients on steroids experience prolonged tapering. A review of 21 studies found that 77 percent of patients were still on

corticosteroids after a year, 51 percent after 2 years, and 25 percent even after 5 years.[19] Another challenge is that relapses and disease flares are common during corticosteroid tapering for PMR; a pooled analysis of 7 studies, which included 384 patients, showed that 43 percent of patients experienced a relapse within the first year.[19]

The tapering process can be straightforward for many patients. However, many PMR patients who fail to respond to initial corticosteroid therapy or who experience disease flares during corticosteroid tapering may benefit from alternate therapies.[20] It's been observed that long-term corticosteroid use can carry risks. Research indicates that toxicity becomes more pronounced when doses are sustained at 5 milligrams per day or higher over time.[21] However, adverse events may occur within just a few days at higher doses and can even arise at doses as low as 2.5 milligrams per day.[22-24]

Dr Turck:
Given what Dr Daniel just talked about, Dr Wright, would you describe some of the side effects associated with corticosteroid use?

Dr Wright:
Of course. So, one of the side effects patients exhibit is change in appearance, and some changes, such as bruising, can greatly impact their daily life. Many patients also describe weight gain and Cushingoid features (and that refers to the weight gain and redistribution of adiposity), which can then affect their self-image and emotional well-being.[25,26]

Another common side effect is diabetes: Corticosteroid treatment is,in fact, the most common cause of drug-induced diabetes mellitus and can increase insulin resistance in patients with comorbid diabetes. These hyperglycemic effects are dose-dependent and occur in patients within hours of exposure.[2 5] Additional risks of long-term corticosteroid use include cardiovascular disease, bone loss and fracture, and cataracts.[25,27]

In fact, caution should be used when considering corticosteroid treatment in patients with comorbidities such as osteoporosis, diabetes, glaucoma, joint infection, and uncontrolled hypertension.[33,34] Corticosteroids also pose greater risks for patients with peptic ulcer disease, congestive heart failure, and active infections,[33,34] and recently it has been shown that corticosteroids may not be suitable for patients with frailty.[25,27] Since these conditions are common in older adults who have multiple comorbidities, many patients may not tolerate corticosteroids and could potentially benefit from alternate therapies.[25,27]

Dr Turck:
Dr Wright, thank you for providing insight on the side effects associated with corticosteroids. And now, if we switch gears and focus on the patient perspective, Dr Daniel, do you have an example of a PMR patient journey you can share with us?

Dr Daniel:
Yes, I do. Let's discuss one of my patients, Anna. Keep in mind that results can, of course, vary from patient to patient.

Anna is a 63-year-old, white female with no known comorbidities or drug allergies. She's employed as an anesthesiologist and was previously active, running about 3 to 5 miles per day. But in November 2022, Anna developed overnight diffuse muscle soreness, localized to her knees. She stopped exercising for 3 months with no improvement, and the stiffness and aches began to spread to her hamstrings.

By March 2023, Anna had difficulty standing from a seated position, and after major surgery that limited her physical activity, she developed increasing myalgia. Just 1 month later, in April 2023, Anna was diagnosed with PMR by her primary care physician and started on 10 milligrams of prednisone since she was 47 kilograms. She experienced a 50 percent improvement in symptoms after 1 day.

This is noteworthy considering her initial lab results showed an ESR of 54 and a CRP of 7.45. So, after showing improvement, 2 attempts were made to taper Anna off prednisone, but both failed, resulting in flares. She then tried methotrexate therapy, which also failed. She was then referred to me, and I started a treat-to-target strategy. In January 2024, Anna started an alternative therapy and was able to taper successfully within weeks. And in January 2025, Anna stopped taking all medication and has successfully maintained corticosteroid-free remission since.

Dr Turck:
Thank you, Dr Daniel, for sharing Anna's story. It is a powerful example of the challenges and the options that patients have in this space. And Dr Wright, what therapeutic approach would you recommend for a typical patient with PMR, like Anna, who might be struggling with corticosteroid tapering?

Dr Wright:

Yeah, so when managing PMR, I focus on setting clear goals with my patients and making treatment decisions together, so we stay aligned on what we're working toward.[30] Once my patients reach remission, I try to keep them there using the lowest dose of medication that still works. So, for me, treating PMR is about keeping symptoms under control, avoiding complications from the disease, and minimizing side effects from the medications, all while keeping their other health issues in mind.

So, for a patient like Anna, who's already had 2 unsuccessful steroid tapers and didn't respond to methotrexate, it's important to pause and talk through her options together. That conversation can help us decide on next steps, including whether another treatment option should be considered, which, as we just heard from Dr Daniel, is exactly what happened.

Dr Turck:
Dr Daniel, now that we've learned more about PMR and potential treatments, let's talk about the importance of patient education. How do you typically approach that with patients?

Dr Daniel:
I'm so glad we are talking about this because patient education is important for empowering patients to take an active role in their own care.[18,25] Discussions with patients should cover PMR basics, such as treatment options and duration, potential side effects, comorbidities, and monitoring needs.[19,27] Clinicians should review treatment pros and cons, including administration routes, and they should personalize care based on patient concerns and preferences.[19,27] And medical consultations can be supplemented with additional patient support resources, including online materials to enhance patient education.[30,31]

When I'm talking with my PMR patients, there are a few topics I usually walk through with them. I start by explaining what PMR is and what the current treatment options look like. We talk about how long treatment might last, what our goals are, and what alternatives we might consider, depending on how things go. I encourage patients to keep track of their symptoms and any side effects from corticosteroids and to let me know right away if anything changes. I also make sure my patients understand how corticosteroids can affect other health conditions and what warning signs to watch for. We'll go over pros and cons of different treatment options and the ways they can be given. And throughout all of this, I try to understand their concerns and preferences, so we can tailor the plan to what matters most to them.

Dr Turck:
Thanks so much for sharing your approach, Dr Daniel. And before we wrap up, Dr Wright, is there anything else you'd like to share with our listeners?

Dr Wright:
Yes, I think it's important to remember that even though corticosteroid treatment can bring quick, symptomatic relief for PMR patients, their long-term use may be associated with adverse consequences, requiring a careful balance of the risks and benefits ratio for treatment management decisions.[3,32,33] Each patient's response to corticosteroid therapy may vary based on their unique circumstances and comorbidities, so adopting a patient-centered, individualized strategy—such as treat-to-target—and exploring alternative therapies can help empower patients to actively engage in their care and improve PMR outcomes.[18,30]

Dr Turck:
That's an excellent point for us to wrap up on. And I want to thank my guests, Drs Rodney Daniel and Grace Wright, for joining me to share their insights.

Dr Daniel, Dr Wright, it was a pleasure speaking with you both today.

Dr Daniel:
It was wonderful to speak with you as well.

Dr Wright:
Thank you for having us.

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