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The importance of patient engagement in the management of giant cell arteritis

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Abstract

Giant cell arteritis (GCA) is a vascular condition characterized by ocular, systemic and neurological symptoms. Visual loss is the dreaded complication of this condition, prompting expedient diagnosis and treatment. Treatment typically involves prolonged glucocorticoid therapy which is often accompanied by several undesired side effects. In this report, we document one patient's experience with GCA, its treatment, and relapse. Particularly, the patient highlights the difficulties and successes he had with the disease and its treatment. We also document the physician perspective on this disease and its treatment, specifically discussing the significance of prolonged treatment with glucocorticoids. We comment on the importance of patient experience and engagement in the setting of GCA and its management, particularly focusing on our recommendations of patient education over multiple visits and individualizing glucocorticoid treatment.

Keywords

Giant cell arteritis, patient engagement, glucocorticoid therapy, prednisone

Introduction

Giant cell arteritis (GCA) is a chronic inflammatory condition of medium to large sized arteries primarily located in the head, neck, and arms. The expected survival from diagnosis is under four years with the incidence of GCA peaking at the age of 70 and rarely being seen in individuals under 50.^{1,2} With sufficient clinical suspicion, oral or intravenous (IV) glucocorticoid treatment should be promptly started, and a temporal artery biopsy is required to confirm the diagnosis.¹

Given the long duration of treatment and the complications associated with prolonged glucocorticoid therapy, active patient involvement is crucial. While an extended glucocorticoid tapering regimen can lower relapse risk, prolonged use of glucocorticoids can cause several side effects including suppression of the hypothalamus-pituitary-adrenal axis.³ In this paper, we hope to highlight the importance of active patient engagement in individualizing glucocorticoid therapy. Active patient engagement involves collaboration between patients, their friends and family, and health care professionals involved in their care.⁴ We invited SR, a

patient with a protracted course of GCA, to share his experience and perspectives to highlight the importance of patient engagement in the management of GCA. Combined with the physician perspective we discuss the key areas of importance for patient engagement in the management of GCA.

General Narrative

SR's Journey with GCA

I had no major health issues until May 2012. Then, I started having a non-stop cough, severe headaches, pain in the jaw, neck, as well as a fever and sweats. My scalp was very sensitive to touch, and I had to put a pillow under my neck instead of my head. I had extreme fatigue and had great difficulty in standing or walking which led to me needing to lie down most of the time. My right eye would go completely blind, but the sight would return after a couple minutes.

Not realizing what was happening, when I travelled overseas to take care of my ailing father, I saw a doctor. He prescribed me capsule-type inhalers, cough syrup and gave some injections. I was feeling very weak and in three

days my right eye went blind twice for a couple of minutes. Meanwhile my headaches and chills were unbearable. Simultaneously, I had an attack of arthritis and all my joints felt frozen. Ultimately, I decided to cut short my six weeks' vacation to just one week and returned to Canada in a wheelchair. When I returned, I saw my family doctor. He had x-rays taken of my chest, which were normal, and he prescribed inhalers which did not work. Cough syrup was effective only for an hour or two.

I did not think my symptoms were severe enough to warrant a hospital visit and was worried I would be wasting hospital resources for just a common headache and cough. At the same time, I felt very desperate and helpless with nothing to look forward to the next morning. Out of this desperation, I remembered I booked an appointment with the ophthalmologist who completed my cataract surgery. After looking at my eye, he sent me to the emergency room as, I was having "mini strokes." Three months later from my initial symptoms, I was seen by Dr. ANES. He looked at my eyes, sent me for bloodwork, and told me I have vasculitis, a condition requiring high-dose steroids, which he started, and he arranged for a temporal artery biopsy. A few days later I had the biopsy where they took a piece of the artery from my head. I was 69 years old when the result came back positive confirming the diagnosis of GCA/vasculitis.

Within 24 hours of taking prednisone, all my symptoms seemed to have disappeared. I was full of energy again and felt like going and digging my garden. However, over time, I realized my GCA symptoms did not disappear completely even with the steroids, and Dr. ANES warned me of the possible side effects I might experience. He would also ask me about these side effects at each appointment, and over time I started to notice these side effects with prednisone. I was tossing and turning all night desperately trying to sleep, sleeping no more than 4 hours per night. I could not stop eating, and my waistline increased from 31 to 34 inches while my face became round and puffy. After being a previous runner, I could not walk more than 400m. My social life suffered tremendously. I could neither make nor receive phone calls, simply because my hands were trembling, unable to support the weight of the receiver. This had a tremendous toll on me, both emotionally and psychologically. I felt I was totally useless. Also, after never having difficulties with my sugars, they went beyond the range of my glucometer. My wife rushed me to the hospital where they put me on insulin infusion. According to the doctors, I also had mild cognitive impairment. The doctor said it could be due to my vasculitis, arthritis, or both. I discussed the impact of the side effects of the steroid treatment on my life with my family and Dr. ANES. He made suggestions for how to cope with some of the side effects which helped me. For example, he suggested trying melatonin for my sleeping difficulties and a medication to

help with my nausea and reflux. However, after multiple years of living with these side effects and mostly resolved GCA symptoms, we ultimately decided to taper my prednisone, eventually discontinuing it. I did well without the prednisone and noticed a marked improvement in my overall quality of life. I was very thankful of Dr. ANES's understanding of the impact the prednisone was having on my quality of life. However, 5 years after discontinuing prednisone I had sharp burning pain and severe shaking in my right thigh, prompting my wife to take me to hospital. With a negative CT head, I was sent home; however, I felt my original symptoms of GCA had returned in a milder form.

Dr. ANES checked my inflammatory markers, and I was ultimately treated with IV steroids for three days, followed by 60mg oral prednisone for relapse of GCA. As can be imagined, this came as deeply disappointing and upsetting news. But this time I knew how to better take care of the side effects. With my family's support, and vigilantly looking for and treating side effects, I slept 6-7 hours, did not feel as hungry, and didn't have any changes to my body. I had enough energy to do the things around the house and work in my garden. Psychologically and emotionally, I am much better now than I was during the initial attack. The only issue I have at present is that my walk is very unsteady, and I cannot walk for more than ten minutes. In my current prednisone taper schedule, I should be finished in the coming months. I am sharing this personal information so that anyone else who may be unfortunate to get GCA may benefit from my experience and understand the importance of speaking with their family and physician to tailor their glucocorticoid therapy to best suit their needs and ensure that side effects are treated when possible.

Physician Perspective

Mr. SR's clinical presentation is typical for GCA. High-dose steroid therapy should not be withheld while awaiting temporal artery biopsy, as there is a risk for visual loss and other vasculitic complications of GCA if treatment is not initiated immediately. Patients must be well-educated about the condition, the potential complications, treatment with corticosteroids and the potential side effects, and the need for serial inflammatory markers.

The British Society of Rheumatology provides guidelines for starting dosages as well as taper of steroids in GCA, however, there is no standard protocol.^{5,6} Given the long-term steroid therapy, patients should be advised to be closely followed to screen for systemic side effects. Common side effects of high-dose corticosteroids include gastric irritation that may result in gastric ulcer and gastrointestinal bleeding, steroid induced hyperglycemia hypertension, insomnia, mood changes, increased appetite, weight gain, cushingoid features, osteoporosis, and ecchymosis. Patients with preexisting conditions such as

diabetes and hypertension must have their blood glucose and blood pressure closely monitored. Gastrointestinal prophylaxis is required, especially if there is a previous history of peptic ulcer disease. Bone density should be monitored and calcium and vitamin D supplements in appropriate cases. Routine ocular screen for steroid-induced complications including glaucoma and cataract is also essential.

With the multitude of steroid-induced adverse effects, patient education will not be complete in just one encounter. Apart from advising the patient to be vigilant to monitor for recurrence of GCA symptoms, it is also crucial for the patients to also watch for the adverse effects of steroids, in order to manage it promptly. It is very important to inform the patient of the possible side effects prior to beginning steroid therapy to obtain informed consent. In my opinion, verbal screening for steroid induced complications should be performed at each patient encounter as well. By implementing these principles, I was able to better understand the impact of the steroid therapy on SR's life, particularly when his quality of life was suffering greatly. Understandably, this is an overwhelming situation from the patient's perspective, as steroids are often considered double-edged sword – the significant benefit of saving vision and other complications of GCA and at the same time to deal with the side effects from the protracted use of prednisone. Patient's insight to the serious vision- and life-threatening diagnosis, and the understanding of the potential side effects of steroids will help the patient to combat the difficulties that may arise after starting the steroid therapy. I encouraged SR to bring family members to his appointments such that they could also be educated on GCA, its treatment, possible side effects, and how best to manage these. I also recognized the strong family support he received and wanted to encourage his reliance on a strong support system. Friends and family play a key role in providing consistent social and emotional support as well as assisting with other factors such as medication adherence.⁷ Physicians should consider the importance of these social factors and encourage patients to actively involve their family and friends in their health where they deem applicable.

Screening for steroid induced complications also requires teamwork, with family physicians, optometrists, and/or ophthalmologists needing to be closely involved in patient care to monitor systemic and ocular side effects of long-term prednisone therapy. If SR's side effects were to become too severe, methotrexate in combination with corticosteroids has been studied as initial treatment of GCA patients as well as in patients with GCA relapse.⁸⁻¹⁰ Tocilizumab, a biological agent has been found to effective in GCA patient in two studies, and it has been approved by the US and European regulatory authorities in the management of GCA.^{11,12}

Reflections and Recommendations

SR's presentation to ophthalmology was consistent with typical GCA symptoms and risk factors. His experience with GCA relapse and prolonged prednisone treatment highlight the importance of active patient engagement in this disease. We hope to have highlighted the importance of communication with the patient about the side effects of glucocorticoid treatment at each physician-patient encounter and the importance of individualizing glucocorticoid treatment based on the impact on the patient's quality of life.

Extended treatment with prednisone, the recommended treatment for GCA, can come with a series of complications.^{13,14} Despite an immediate short-term gain in energy and functionality following prednisone initiation, over time, SR's sleep quality, glucose and weight regulation, strength, and social situation greatly deteriorated. Long term treatment with glucocorticoids for GCA can lead to the development of obesity, diabetes mellitus, gonadal dysfunction, hypertension, fluid retention and pedal edema, weakness, and osteoporosis.^{13,15} The significant impact these side effects can have on a patient's quality of life are an important factor to consider when planning appropriate management. For example, weight loss is an effective treatment for diabetes and reduces some of the risks associated with obesity, however, would be very difficult for a patient who is also dealing with fatigue and weakness.¹⁶ Thus, it is especially important to actively engage patients to determine which aspects of their diagnosis or complications caused by treatment cause the largest impact to their quality of life. Incorporating questions about quality of life and asking patients about what symptoms, GCA-related or prednisone-related, into the routine GCA patient interviews can be very beneficial in individualizing steroid therapy for the patient. Providing support and resources to assist with lifestyle modifications is also crucial. For example, sleep quality can be impacted by many factors, some of which are modifiable, such as the use of melatonin. Gastrointestinal prophylaxis is similarly important. Furthermore, tocilizumab and methotrexate may be viable alternative treatments for patients who experience significant complications because of long-term glucocorticoid treatment that severely reduce their quality of life.^{17,18}

Involving patients in the management of their health has been shown to improve outcomes and be a key component of effective healthcare.^{19,20} As evidenced by SR's story, GCA can cause significant changes to a patient's quality of life, with symptoms lasting for an extended period despite long-term treatment, potential to relapse even after treatment and recovery, and additional symptoms caused as a side effect of prolonged glucocorticoid treatment. The fear and anxiety of possibly having a relapse can contribute to the psychological impact

of a GCA diagnosis.²¹ GCA relapses are not uncommon, with some estimates ranging from 43% to 80% of GCA patients experiencing a relapse.²² By understanding the significance of a relapse and the difficulties that come as a result of the diagnosis, physicians can involve the patient to better tailor management strategies to address these concerns.

In modern times, increased importance has been placed on the role of the patient perspective in the management of chronic disease. Recently, a disease specific patient-reported outcome measure has been developed to better understand a patient's experience with GCA and may play an important role in future clinical trials and eventually clinical practice.²³ It is important to highlight that any individual's journey with GCA or a prolonged glucocorticoid treatment is unique, and management should reflect this fact. Interestingly, patients who are actively engaged in the management of their chronic condition often lead their healthcare team to deliver more responsive care.²⁴

In conclusion, the perspectives shared by SR and ANES demonstrate the crucial role of patient engagement in ensuring optimal clinical outcomes. Particularly, we have highlighted the importance of patient education about the side effects of prolonged glucocorticoid therapy and recommend verbal screening for side effects at every patient encounter. Furthermore, we stress the importance of individualizing glucocorticoid therapy in patients who may be experiencing a serious impact on their quality of life while on prednisone.

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