

**The patients' perspective of important glucocorticoid effects: A nominal group study amongst patients with systemic lupus erythematosus and myositis**

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**Abstract:****Background:**

Glucocorticoids (GCs) are used in the treatment of systemic lupus erythematosus (SLE) and myositis to control disease symptoms, but can have significant adverse effects. While physicians recognize some of these effects, little data exists surrounding the perspectives of patients with SLE and myositis on GC effects. The objective of this study is to understand the positive and negative effects of GCs in patients' with SLE and myositis from the patients' perspective.

**Methods:**

Patients with SLE or myositis were asked to participate in five nominal groups where demographic information and a quality of life questionnaire was completed. Patients were asked two open-ended questions on 1) benefit and 2) harms related to GC use. Nominal Group Technique (NGT), a highly structured consensus method in which responses are generated, shared, clarified and ranked. Descriptive statistics were used to summarize the results.

**Results:**

Of 206 patients who were approached, 21 patients participated, 17 with SLE and 4 with myositis, predominantly women with >20 years of steroid use. The domains ranked highest for GC benefits were disease control (55 votes), fast-acting (30 votes), increases energy (10 votes) and pain relief (10 votes). The highest ranked negative effects were bone loss (38 votes) and weight gain (16 votes); psychological effects and damaged internal organs each received 12 votes.

**Conclusions:**

The top ranked GC effects-both benefits and harms-among patients with SLE and myositis are consistent with the top domains associated with GC use in other inflammatory diseases. This study supports the development of a comprehensive patient reported outcome measure that can be used across inflammatory diseases.

## **Introduction:**

Systemic glucocorticoids (GCs) are widely used to treat many inflammatory diseases, and are a mainstay in the therapy of systemic lupus erythematosus (SLE) and the inflammatory myopathies.<sup>1-4</sup> While GCs are generally effective at controlling disease activity, they additionally have both positive and negative impacts upon health and quality of life.<sup>5-9</sup> Some adverse events (AEs) – such as osteoporosis, weight gain, and diabetes are well recognized and can be measured by physicians. However, there may be other effects of GC therapy that concern patients such as skin thinning, sleep disturbance and anxiety that have traditionally not been as well quantified by physicians.<sup>10</sup> Previous research by the European League Against Rheumatism (EULAR) and the Outcome Measures in Rheumatology (OMERACT) taskforces have recognized a need to systematically quantify the effects of GCs across patient groups. The EULAR group on GC effects has published two systematic literature reviews,<sup>11,12</sup> and has developed the Glucocorticoid Toxicity Index (GTI), but the GTI does not include patients' perspectives.<sup>13</sup> Therefore, it is possible that the GTI fails to capture some of the effects of GCs that are of importance to patients. Discordance between physicians and patients is common in healthcare and suggests that patients may also perceive and prioritize GC effects very differently from providers.<sup>14</sup> Ultimately, the development of a patient reported outcome (PRO) that specifically addresses the positive and negative effects of GCs on patients' health, quality of life and overall lived experience, would complement the GTI and aid physicians in assessing treatment effect with GCs alone but also in comparison to other steroid-sparing therapies.

As new therapies are developed, their efficacy and adverse effects are compared to those of 'standard of care' medications. For this reason, the OMERACT GC special interest group (SIG) met in 2016 and 2018 to set a research agenda with the goal to work towards creating a PRO that effectively quantifies all systemic GC related effects and AEs across inflammatory rheumatic diseases.<sup>10,15</sup> At present, studies have identified the impacts of GCs in patients with rheumatoid arthritis (RA), Polymyalgia rheumatic (PMR), giant cell arteritis (GCA) and ANCA-associated vasculitis.<sup>10,16</sup> These studies show that weight gain, sleep disturbance, thin skin/easy bruising, and upset stomach are among the most worrisome effects to patients with these diseases. Yet, the effects of GCs in patients with SLE and myositis from the patients' perspective have not been studied.

The aim of this study, was to utilize nominal group technique (NGT) to identify and prioritize the effects of GCs, both beneficial and harmful, which are of importance to patients with SLE and the inflammatory myopathies.

## **Methods:**

### *Recruitment*

Individuals over the age of 18 with a diagnosis of SLE or an inflammatory myopathy and meeting American College of Rheumatology (ACR) classification criteria or Bohan and Peter criteria, respectively were recruited from rheumatology practices at the Hospital for Special Surgery, New York, NY. In addition to meeting classification criteria, participants had to be currently or previously taken systemic GCs. Those with overlapping rheumatic diseases were not excluded. Individuals were identified by their rheumatologists, contacted by telephone or e-mail and invited to participate. The participants received a payment in consideration of their time, parking or transportation was reimbursed, and snacks were served during the sessions.

Prior to the start of the nominal group, participants completed a questionnaire to capture demographic data and to determine their exposure to GCs. The participants also answered the Patient-Reported Outcomes Measurement Information System (PROMIS) Global-10 questionnaire, a validated tool used to assess general domains of health.<sup>17</sup> The questionnaire is comprised of 10 questions and scores are summarized as the global mental health score and global physical health score. Scores are reported as percentiles, with higher scores indicating better status.

### *Description of NGT*

NGT is a variant of the traditional focus group and is an effective method for studying specific questions in a detailed manner.<sup>18</sup> This method has been used to study the patients' perspective across many different diseases.<sup>19-27</sup> NGT is a consensus building method that can be used to efficiently establish and rank important effects through responses to open ended questions. The participants list, discuss, and then prioritize the responses during the sessions, ultimately voting on the nominated responses, producing a ranked list.

The nominal group (NG) discussions lasted approximately two hours, and two questions were answered, approximately one hour per question. An experienced leader (SG) and assistant (SM) led the groups. The two questions were selected for the patient groups after discussion and informal testing by the investigators. After introductions, the group leader explained the focus of the session and then described the process for the participants.

The first question assessed the benefits of GCs from the patients' perspective, 1) "In addition to the impacts on your illness, what effects are the most important to patients who are taking steroids?". The second question inquired about potential harms of GC use, 2) "What do you think are the most significant unwanted effects or harm from taking steroids?". The questions were discussed sequentially, one at a time. After clarifying any questions from the group, the patients were asked to independently write down as many responses as possible to the question from their own perspective. Then, in a round-robin fashion, the responses were reported and

recorded on a flip board. As a group, the responses were expanded upon through discussion and, when necessary, collapsed when responses addressed the same domains. Finally, each patient recorded the three domains on an index card that he or she thought were the most significant, taking into consideration the perspective of all patients with SLE and/or an inflammatory myopathy and were each given 6 votes to distribute among the nominated responses. The top response was given three votes, the next two votes and the last one vote. The votes from all participants were subsequently tabulated, establishing the rank order. The project was completed when thematic saturation was achieved.

### *Statistical Analysis*

Baseline data was analyzed using descriptive statistics. Steroid dosage was converted to prednisone equivalent. PROMIS Global-10 scores were calculated using a publicly available online calculator <http://orthotoolkit.com/promis-10/>, and were reported as global physical and mental health scores. <sup>28</sup>

The study was approved by the Hospital for Special Surgery's Institutional Review Board and all participants gave informed consent to partake in the study.

### **Results:**

#### *Patients:*

We identified 206 individuals, and called/e-mailed 158 of whom 101 responded and 48 unable to reach by phone or email. Thirty-five patients were interested in the study and a total of 21 patients participated. The groups included 17 patients with a diagnosis of SLE and four with myositis who participated in five NG discussions from April 9<sup>th</sup> 2019 to May 9<sup>th</sup> 2019. The mean age of all participants was 46.0 years (42.5 years for the SLE group and 61.0 years for the myositis group). Nineteen participants were female and most patients had experience taking GCs for more than 20 years, with 13 participants currently remaining on oral GCs. Those with SLE were on a mean current prednisone equivalent dose of 8.2 mg while those with myositis 2.4 mg. Sixteen patients with SLE and three with myositis reported being afraid of long-term side effects and two participants reported that they enjoyed taking GCs. Overall if given the option to increase, decrease or to not change their dose of steroids, one reported that they would increase their dose, 15 would decrease their dose and 5 would not change their dose. **(Table 1)** The mean  $\pm$ SD PROMIS10 physical health score for the SLE group was 57.6 $\pm$ 11.7 and 60.0 $\pm$ 7.1 for the myositis group. The mental health scores were 57.4  $\pm$ 15.1 and 62.5 $\pm$ 15.5, respectively. **(Table 1)**

#### *Summary of votes:*

Question 1 *"In addition to the impacts on your illness, what (beneficial) effects are the most important to patients who are taking steroids?"*

The first question considered the benefits of GCs, receiving a total of 126 votes. The domains voted on for the most important benefits of GCs were: 1. controls disease and symptoms (55 votes), 2. works fast (30 votes), 3. increases energy (10 votes)

and 4. relieves pain (10 votes). Additional items included: 5. thinking clearer (4 votes), increased appetite (1 vote), affordable (3 votes) and 9 votes from the first group who listed harms not benefits. The least voted on domain was: 6. flexibility of use (4 votes).

Question 2, *“What do you think are the most significant unwanted effects or harm from taking steroids?”*

This question received 126 votes. The most highly ranked domains were: 1. bone loss (38 votes), 2. weight gain (16 votes), 3. psychological effects (12 votes), and 4. damaged internal organs (12 votes). Additional domains were: 5. other (10 votes), 6. dependence (9 votes), 7. physical appearance (7 votes), 8. sleep disturbance (6 votes), 9. weakness of muscles and ligaments (6 votes), 10. increased risk of infection (6 votes), and 11. eye problems (4 votes). The following items were voted on in the other category: high sugar (2 votes), height (2 votes), teeth problems (2 votes), skin thinning (1 vote), high cholesterol (1 vote), lack of compatibility with other drugs (1 vote) and difficulty concentrating (1 vote). The full summary scores are available in **Table 2**.

*Summary of domains:*

In this study, patients with SLE and myositis ranked GC effects according to the importance to them. Most important was the effectiveness of GCs to control the symptoms of SLE or myositis. This domain received a total of 55 votes and was voted for in three of the five groups. Important disease symptoms that patients mentioned were inflammation, morning stiffness, lack of mobility, rashes, flares, and low quality of life, all of which were improved by taking GCs. One patient mentioned that GCs help her “get through the day,” and without it, “ You can’t go about normal activities of the day like brushing your teeth, blow drying your hair and being able to work”. Another patient spoke about GCs controlling rashes. She said, “When I flare up I break out in rashes. As soon as I take it or when my doctor increases the prednisone, within 24 hours the rash is gone.” A third patient said that GCs “kept me stable so I can have a full time job. I can be in my 20s in New York, can travel and I don’t think I could do any of those things without it.”

The speed of onset of GCs received the second highest number of votes. Three of five groups mentioned that GCs “working fast” as an item of importance, with a total of 27 votes. Patients who voted on this domain said that GCs lead to “fast symptom relief” and “it helps cure the immediate medical diagnosis”. One patient said, “My foot will be swollen and 20 minutes after taking it I can get up”. Another patient said that GCs sped up the healing process itself. She said, “Whatever I got pertaining to lupus – it made the healing process faster”.

Feeling energetic and pain relief were the next most important effects voted on and they each received 10 votes. Both domains were voted for in three of the five groups. Under the energy domain, patients mentioned having an “increase of energy level” as one of the most important effects of GCs. Patients who voted on this

domain said, "It increases the ability to move about because of the energy." Another patient mentioned that GCs "helps me feel stronger physically. You don't feel old – sometimes I do and when you take it that feeling goes away." For pain relief patients mentioned a decrease in joint pain and complete elimination of pain.

Patients ranked the flexibility of taking GCs as the domain with the next highest importance, with a total of four votes. However, this was only voted on in two of the five groups. Under this domain patients described the flexibility as being able to take GCs as needed, taking GCs while pregnant and the ability to self-manage their dose, increasing and tapering as needed. While patients agreed this was an important characteristic of GC use, their experiences with the flexibility of GCs varied. One patient was able to stop taking steroids as she wanted and said, "I just didn't want to take it anymore and didn't have any side effects or anything. I haven't been on it in 10 years." While another patient had more difficulty, and said, "Every time I try to go down to 1 mg and try to go off of it, it causes problems or difficulties...every time I tried to go down I had to come back up."

Other items that patients voted on as being important to them were the ability to help them think more clearly (four votes), give them an increased appetite (one vote), and affordability (three votes). All three of these items were only voted on in the third NG. **Appendix Table 1** shows the complete list of quotations and votes for each NG.

Amongst the most important harmful effects of GCs, bone loss received the most votes. This item was voted for in all five NGs and received a total of 31 votes. Patients who voted for this category discussed general bone damage, osteoporosis and avascular necrosis (AVN). A patient with AVN said, "For me it's AVN. I'm 27 and I'm asking why do I have this and it's because I've been taking it (GCs) for 10 years. And I go to the gym a lot so what's going to happen at 65". Another patient showed a similar fear from bone loss and said, "That's what makes me not want to take it – it's supposed to make me feel better, but it's also destroying my bones".

After bone loss, weight gain was the next most important domain and received 14 votes. This domain was mentioned in four of five groups. Besides general weight gain, patients also discussed common GC side effects, such as moon face and an increase in appetite. One patient also mentioned fat re-distribution with a buffalo hump, however this was viewed as a separate category under physical appearance and received no votes.

The psychological effects domain received 12 votes and was voted for in three of the five groups. Within this domain, patients mentioned moodiness and mood instability, depression and anxiety, irritability, and feeling "uncomfortable with myself". For example, one patient said, "My mom would always ask me why are you angry and I would just say because I am - I don't know."

Though patients mentioned feeling a sense of flexibility with GCs in the first question, they also voted feeling dependent on the medication as a negative consequence in the second question. Dependence received a total of nine votes and was voted for in two groups. Within those groups, patients mentioned a danger of suddenly stopping GCs, long tapering periods and feeling “addicted” to the medication.

The issue of physical appearance received seven votes and was mentioned in three of five groups. The items under this domain included a general change in physical appearance, excessive hair growth, moon face, and buffalo hump. One patient described this issue as, “a big issue for everyone”. She said, “You can hide the stuff that’s going on the inside. When it starts to manifest in your physical appearance its harder to hide.”

The other domains that received votes under this question include: sleep disturbance, muscle and ligament weakness, infection, internal damaged organs, eye problems, high blood sugar, skin thinning, high cholesterol and blood pressure, teeth problems, lack of compatibility with other drugs and difficulty concentrating. It is important to note that 3 groups voted on internal damaged organs, two of the groups voted specifically on stomach irritation. The third group voted generally on internal damaged organs and when asked to expand upon the item, mentioned kidney damage. One patient who began GCs at age four mentioned and voted for stunted height/growth as an important harmful effect of GCs. **Appendix Table 2** includes a complete list of quotations and votes for each domain voted on in question two.

### **Discussion:**

Amongst patients with SLE and the inflammatory myopathies, the domains with the highest number of votes related to the benefits of GCs were the ability to control the disease and associated symptoms, the ability of GCs to resolve these symptoms quickly, an increase in energy, and pain relief. In contrast, the highest-ranking domains for the unwanted or harmful effects were bone loss and damage, weight gain, psychological effects, and damaged internal organs (stomach and kidneys).

Overall, this study shows that the most important beneficial and harmful effects of GCs on patients with SLE and myositis are similar to those in other inflammatory conditions. Previous qualitative studies <sup>10</sup> amongst patients with RA and vasculitis, GCA and PMR show that the top benefits of GC use are their ability to effectively treat disease symptoms and their ability to provide rapid relief of symptoms. However, other studies have reported an increase in energy as a harmful side effect of GCs. <sup>29</sup> This is contrary to our study, where patients ranked an increase in energy as the third most important benefit. Importantly, when we asked patients to expand upon this item, most reported that the increase of energy allowed them to participate in life and daily activities as they wished.



More studies have focused and reported on the harmful side effects of GC use in patients with inflammatory conditions.<sup>10,16,29</sup> to our results, bone loss, weight gain and psychological effects were amongst top unwanted effects of GC use. Some studies<sup>10,16</sup> showed skin thinning and bruising amongst top effects, while this item only received 1 vote in our study. This difference could be due to a small number of participants. Additionally, within the category of bone loss, several patients in our cohort mentioned AVN as a specific issue, which was not specifically mentioned in previous studies amongst patients with other rheumatic diseases, likely owing to the fact that SLE patients are at higher risk of AVN development than other rheumatic diseases.

The study strengths are that all patients included met either SLE or myositis classification criteria. Further, to our knowledge, this is the first study using NGT to ask patients with lupus and myositis of both the benefits and harms of GCs. The weaknesses of this study include a low number of patients, especially in the myositis group. Recruiting large amounts of myositis patients for studies is difficult given the rarity of the condition itself. However, the patients that were included met either myositis or SLE ACR classification criteria, which improves sample homogeneity.

Additionally, NG one only included two participants, who focused exclusively on the harms of GCs.

Previous qualitative research performed with patients with SLE by Mathias et al<sup>30</sup> included concept elicitation of medication effects for SLE symptom domains of importance and queried GC dose, but did not address both beneficial and harmful effects of GC. Our study specifically addresses GC effects in patients with SLE or myositis. Additionally, in a review of patients with SLE by Holloway et al,<sup>31</sup> 27 symptoms and impacts of SLE were identified, but medication effects were again not addressed. This study did evaluate the patient-reported outcome of GC effects in SLE and myositis patients, which our study attempted to explore.

In conclusion, our results show that the top three most important effects or benefits of GCs to patients with SLE and myositis were the GCs' ability to control the disease symptoms, do so in a quick manner and increase energy. The top three most harmful effects in this patient population were bone loss, weight gain and psychological effects. These effects are similar to benefits and harms across several different rheumatic diseases. Thus, clinicians and patients could both benefit from the development of a comprehensive patient-reported outcome measure to quantify the overall effects of oral GCs.

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Table 1. Baseline Characteristics

	SLE N=17	Myositis N=4	Combined N=21
Age, (mean ± SD)	42.5 ± 14.4	61.0 ± 15.5	46.0 ± 15.7
Sex, Female, n (%)	15 (88.2)	4 (100.0)	19 (90.5)
Race, n (%)			
White	3 (17.6)	3 (75.0)	6 (28.6)
Black	8 (47.1)	-	8 (30.1)
Asian	5 (29.4)	-	5 (23.8)
Hispanic	1 (5.9)	-	1 (4.8)
Disease duration, n (%)			
<2 years	-	1 (25.0)	1 (4.8)
2-5 years	1 (5.9)	-	1 (4.8)
5-10 years	7 (41.2)	-	7 (33.3)
10-20 years	4 (23.5)	-	4 (19.0)
> 20 years	5 (29.4)	3 (75.0)	8 (30.1)
Currently using steroids, Yes n (%)	9 (52.9)	4 (100.0)	13 (61.9)
Steroid dose*, mg (mean ± SD)	8.2 ± 3.9	2.4 ± 1.0	6.3 ± 4.1
Duration of steroid use, n (%)			
< 6 months	3(17.6)	-	3 (14.3)
6 months – 1 year	1 (5.9)	-	1 (4.8)
1-5 years	1(5.9)	1 (25.0)	2 (9.5)
5-10 years	3 (17.6)	-	3 (14.3)
>10 years	9 (52.9)	3 (75.0)	12 (57.1)
Do steroids help with pain? Yes n (%)	15 (88.2)	4 (100.0)	19 (90.5)
Are you afraid of long-term side effects? Yes n (%)	16 (94.1)	3 (75.0)	19 (90.5)
Do you like steroids? Yes, n (%)	2 (11.8)	-	2 (9.5)
If your physician wanted to change the dose what would you do? n (%)			
Increase	1 (5.9)	-	1 (4.8)
Decrease	12 (70.6)	3 (75.0)	15 (71.4)
No change	4 (23.5)	1 (25.0)	5 (23.8)
PROMIS global physical health	57.6 ± 11.7	60.0 ± 7.1	58.1 ± 10.6
PROMIS global mental health	57.4 ± 15.1	62.5 ± 15.5	58.3 ± 14.6

\* steroid dose reported as prednisone equivalent.

SD = standard deviation. N = number of participants. SLE = systemic lupus erythematosus

Table 2. Summary scores for questions 1 and 2

<b>Question 1: In addition to the impacts on your illness, what effects are the most important to patients who are taking steroids?</b>	
<b>Domain</b>	<b>Total votes</b>
Controls disease/symptoms	55
Works fast	30
Other *	17
Energy	10
Pain Relief	10
Flexibility of use	4
<b>Question 2: What do you think are the most significant unwanted effects or harm from taking steroids?</b>	
<b>Domain</b>	<b>Total votes</b>
Bone loss	38
Weight gain	16
Psychological effects	12
Damaged organs	12
Other	10
Dependence	9
Physical appearance	7
Sleep disturbance	6
Weakness	6
Infection	6
Eye problems	4

\*Includes 9 votes from group 1 who did not answer the question correctly.

Appendix Table 1. Responses to Question 1 “**In addition to the impacts on your illness, what effects are the most important to patients who are taking steroids?**”

NG #1: 4/9/2019, 3:00 PM. 2 Female. 1 African-American, 1 White. 12 votes*	
<p>F. <b>Other:</b> Insomnia</p> <ul style="list-style-type: none"> <li>• Big issue for me – still is, in general it’s a quick fix and helps with symptoms after taking it for a while</li> <li>• I’m not rested for periods of time; tend to go into a fatigue syndrome. Groggy during the day and not always clear. You’re not in your best mood and feel always tired.</li> <li>• If don’t sleep – I won’t sleep for days in a row.</li> <li>• So exhausted from doing day-to-day things that you have to do.</li> <li>• Exhausted or fatigue from lupus gets to you, I need to take Ambien</li> </ul>	2
<p>F. <b>Other:</b> Avascular Necrosis</p> <ul style="list-style-type: none"> <li>• Have it in both hips, after a whole year I wasn’t getting any better and needed a hip replacement.</li> </ul>	2
<p>F. <b>Other:</b> Acne</p> <ul style="list-style-type: none"> <li>• Feel like going back to being a teenager.</li> <li>• In my adolescence I never suffered with acne, come to my 30s and all of a sudden it’s like what is going on with my face.</li> <li>• Also have complexion changes. My skin is quite different from before to now.</li> <li>○ <i>Changes in skin/facial features.</i> <ul style="list-style-type: none"> <li>• <i>I have a round face, beaver face. My hair and eyebrows started getting darker, and I’m thinking this is terrible.</i></li> </ul> </li> <li>○ <i>Peach fuzz/unwanted hairs</i> <ul style="list-style-type: none"> <li>• <i>For me it shows up on the side of my face. It’s frustrating and comes down to affecting physical appearance.</i></li> <li>• <i>I don’t tell anyone, I find that I can’t control most of what goes on, but I can control who I tell about it – I don’t like it when it starts affecting your physical appearance.</i></li> </ul> </li> </ul>	4
<p>C. <b>Works fast:</b></p> <ul style="list-style-type: none"> <li>• Especially when I was really struggling with infusion treatments. I have three within a week of 1000.</li> <li>• It’s a known evil, but you know it will help.</li> <li>○ <i>Helps with issues relatively quickly.</i> <ul style="list-style-type: none"> <li>• <i>Helps with other issues that you have too. It controls my asthma – didn’t have to use inhaler and helped with allergies</i></li> <li>• <i>Helps with migraines. Your body adjusts, I’m already down to 10 mg a day and my headaches are worse, everything comes back but you don’t want to go back up.</i></li> </ul> </li> </ul>	3
<p>F. <b>Other:</b> Can’t stop taking it suddenly</p>	1

<ul style="list-style-type: none"> <li>• Everything is worse off when you suddenly stop taking it</li> </ul>	
NG #2: 4/10/2019, 4:30 PM. 2 Female, 1 Male. 3 African American. 18 votes.	
C. <b>Works fast:</b> Made healing process faster	7
<ul style="list-style-type: none"> <li>• Healing from anything. Whatever I got pertaining to lupus – it made the healing process faster. Without steroids it would take months to heal from a paper cut</li> </ul>	
B. <b>Pain Relief:</b> Less joint pain	6
A. <b>Energy:</b> Increase in energy level	5
<ul style="list-style-type: none"> <li>• For a long time I had a problem with fatigue</li> <li>• Feel like I can do almost anything</li> <li>• At higher doses keeps me awake at night – harder to fall asleep and stay asleep.</li> </ul>	
NG #3: 4/29/2019, 4:00 PM. 6 females. 2 white, 2 African American, 2 Asian. 36 votes.	
C. <b>Works fast:</b>	12
<ul style="list-style-type: none"> <li>○ <i>Fast symptom relief</i></li> <li>○ <i>Helps cure the immediate medical diagnosis</i> <ul style="list-style-type: none"> <li>• <i>Wake up quite a bit to move around due to pain, especially in my upper joints, I have a deep sleep when I'm on the steroids.</i></li> <li>• <i>It's the discomfort that wakes me up. I have other pain medications that I use during major flare-ups.</i></li> </ul> </li> <li>○ <i>High dose works quickly</i> <ul style="list-style-type: none"> <li>• <i>Can get good response with lower doses/shorter courses</i></li> </ul> </li> </ul>	
E. <b>Controls disease:</b> Reduces inflammation	11
F. <b>Other:</b> Think clearer	4
<ul style="list-style-type: none"> <li>• Some days I'm in a fog and during the periods I'm on steroids I can focus better</li> <li>○ <i>Can think better</i></li> </ul>	
A. <b>Energy:</b>	3
<ul style="list-style-type: none"> <li>• Gives you so much energy</li> <li>○ <i>Increases ability to move about</i> <ul style="list-style-type: none"> <li>• <i>Because of the energy</i></li> </ul> </li> </ul>	
B. <b>Pain relief:</b> Takes the pain completely away	2
<ul style="list-style-type: none"> <li>○ <i>Pain relief</i></li> <li>○ <i>Reduces pain</i></li> </ul>	
F. <b>Other:</b> It gives me an appetite	1
F. <b>Other:</b> Reasonably cheap, we can afford it.	3
<ul style="list-style-type: none"> <li>• Have to take it for a long time so it could be expensive</li> </ul>	
NG #4: 5/7/2019, 4:30PM. 7 females. 2 white, 3 African American, 2 Asian. 42 votes.	
E. <b>Controls disease:</b> Keeps inflammation down.	14

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- Inflammation in my knees, sometimes my back – I'll be stuck and can't do anything. After 20 minutes of taking it I can grab something and move.
  - *Helps get rid of pain*
  - *Controls the rashes*
    - *When I flare up I break out. As soon as I take it or when my doctor increases the prednisone, within 24 hours it's gone. I know I'm having a flare up because of my rash and then I start to feel the physical stuff – that's the only good thing about it.*
  - *Only thing that works to control flares*
    - *It starts to immediately manifest in pain cycle, shortly followed by fevers. That's what makes it possible for me to have a life. I have arthritis as a complication of macrophage syndrome so it's the only thing that works*
  - *Controls fevers*

E. **Controls disease:** Overall increases quality of life.

12

- I have a 4 year old and a 5 year old and I'm able to get on the floor with them and ride bikes with them, it's the steroids that allow me to do that
- *Can get through the day*
  - *Gives you a burst of energy, without it you can't go about your normal activities of the day, brushing your teeth or drying your hair*
  - *Means I don't feel the need to lie down and rest*
- *Able to play with kids*
- *It helps me feel stronger physically*
  - *After I take it – you feel it*
  - *Its an extra energy, a boost*
  - *I can walk up stairs easily*
  - *You don't feel old – sometimes I do and when you take it you don't feel that way*
- *You can increase it if the level you're at isn't working*
- *I can blow dry my hair*
  - *I'm not standing over the counter trying to blow dry my hair*
  - *Overall better quality of life, I can do everything I need to do*
- *Can brush my teeth*
- *Increases appetite*
  - *I don't have a good appetite so it helps – even bread tastes so delicious.*
- *Kept me stable so I can have a full time job*
  - *Can be in my 20s in New York, can travel and I don't think I could do any of those things without it.*
- *Can travel*
  - *Even if I don't take it for 10 years, if I travel I know it's with me. Makes me feel secure*
- *Allows me to live the life I want*
  - *It keeps me alive*

C. **Works fast:** It works very quickly

8

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- 
- My foot will be swollen and 20 minutes after taking it I can get up
  - *Helps with the flare up*
- E. **Controls disease:** Can move 4
- *Able to walk*
    - *I was bed ridden and I took the steroids and was able to walk the next day. It was everything – the pain and weakness. I couldn't walk and I didn't know why and once I was diagnosed and prescribed prednisone I was able to walk the next day*
  - **Energy:** More energy 2
    - *Energy*
    - *Can get through the day*
    - *Gives you a burst of energy, without it you can't go about your normal activities of the day, brushing your teeth or drying your hair*
    - *Means I don't feel the need to lie down and rest.*
    - *Improves fatigue*
    - *It helps me feel stronger physically*
    - *After I take it – you feel it*
    - *Its an extra energy, a boost*
    - *I can walk up stairs easily*
    - *You don't feel old – sometimes I do and when you take it you don't feel that way*
- D. **Flexibility for use:** Can always get back on it – always there for an option 1
- *Not always a happy option, but it's there for emergencies*
  - *Available just in case*
    - *Gives security*
    - *Flexibility*
    - *Allows you to control the pain*
- D. **Flexibility for use:** Can take it when your pregnant 1
- *During my second pregnancy I was very paranoid to take it while I was pregnant*

NG #5: 5/9/2019, 4:30PM. 3 females. 1 white, 1 African American, 1 Asian. 18 votes.

- E. **Controls disease:** Will control disease 8
- *It's the only thing that makes me happy - taking steroids. You're comforted that you will get better*
- E. **Controls disease:** Makes you feel better 3
- *Makes me good to go*
  - *Helps me function*
    - *It's bad but I do rely on it more because the meloxicam is there everyday. It's bad but its good too and I've been on it since 2003 or 2004*
- E. **Controls disease:** Helps with morning stiffness 3
-

A. <b>Pain relief:</b> Helps pain	2
○ <i>Pain relief</i>	
• Last January I started 60 mg and have 5 infusions. Now I'm taking half and I'm really hoping to get off of it because the side effects were awful	
• I needed to connect with my PCP and try to get off steroids.	
D. <b>Flexibility for use:</b> Able to self manage dose	1
• I just didn't want to take it anymore and didn't have any side effects or anything. I haven't been on it in 10 years	
• Every time I try to go down to 1 mg, every time I try to go off of it its been a problem and difficult. Every time I tried to go down I had to come back up – I'm at 5 and I want to get off the 5	
• Once you're on a higher dose you can't stop taking it. I was on 5 mg and from there I started to cut it out	
D. <b>Flexibility for use:</b> Can take for short period/do not have to take forever	1
Total: 126 votes	
*9 of the 12 votes within NG1 were not applicable to the first question and were grouped under the other domain.	
NG = nominal group; PCP = primary care physician.	
A = Energy; B= Pain relief; C = Works fast; D = Flexibility of use; E= Controls disease; F = Other	

Appendix Table 2. Responses to Question 2 “**What do you think are the most significant unwanted effects or harm from taking steroids?**”

NG #1: 4/9/2019 3:00 PM. 2 Female. 1 African-American 1 White. 12 votes.	
C. <b>Physical appearance:</b> Changes in physical appearance	4
<ul style="list-style-type: none"> <li>• Would be a big issue for everyone. You can hide the stuff that’s going on the inside, when it starts to manifest in your physical appearance its harder to hide.</li> </ul>	
○ <i>Weight gain</i>	
<ul style="list-style-type: none"> <li>• <i>People ask me if I’m expecting again – always goes to mid section of body</i></li> </ul>	
B. <b>Bone loss:</b> Issues between bone density loss and possible AVN.	3
<ul style="list-style-type: none"> <li>• Impacts how you work, livelihood and social life. If you have small children and they want to play etc. you’re left out. You feel like you can’t be there for them</li> </ul>	
○ <i>Bone density</i>	
<ul style="list-style-type: none"> <li>• <i>Having to take calcium pills – they’re huge but you know why you’re taking it.</i></li> </ul>	
D. <b>Damaged organs:</b> Stomach distress	2
<ul style="list-style-type: none"> <li>• Helped or increases distress – it still affects your stomach</li> </ul>	
E. <b>Infection:</b> Increase risk of infections	2
<ul style="list-style-type: none"> <li>• I stay clear of people who I view are sick. It helps with other treatments and avoiding being sick</li> <li>• My daughter got sick, the next day I was throwing up and then had to go to the hospital</li> <li>• Don’t pick up a lot of colds, but do pick up weird side effects/allergies</li> </ul>	
I. <b>Dependence:</b> Can’t stop taking it suddenly	1
<ul style="list-style-type: none"> <li>• You cant decide going from 100 mg to 0 mg tomorrow. Effects of suddenly stopping it is very risky</li> </ul>	
NG #2: 4/10/2019, 4:30 PM. 2 Female, 1 Male. 3 African American. 18 votes.	
B. <b>Bone loss:</b> Loss of bone (and brittleness)	7
<ul style="list-style-type: none"> <li>• I did bone density scan and they told me the bone density was getting lower and lower – but I never had a fracture or a break</li> </ul>	
○ <i>Bones get brittle</i>	
<ul style="list-style-type: none"> <li>• <i>I was on crutches for a year because I was much heavier and the doctor told me to lose weight and I had necrosis of my left hip – it was really painful</i></li> <li>• <i>I taught myself to walk without crutches because it wasn’t cute</i></li> <li>• <i>I’m not a big fan of going under the knife; I’m scared to have the surgery</i></li> <li>• <i>I have no cartilage in my hip anymore</i></li> </ul>	
A. <b>Weight gain:</b>	2
<ul style="list-style-type: none"> <li>• Easier for your bones to break if you gain a lot of weight</li> <li>• I went up to a size 12 so I know</li> </ul>	
F. <b>Eye problems:</b> Trouble with vision	1
<ul style="list-style-type: none"> <li>• Not sure if it was from prednisone or plaquiniel</li> </ul>	



D. <b>Damaged organs:</b> Internal damage that it does to your organs	8
<ul style="list-style-type: none"> <li>• Occurs with long-term use</li> <li>• Kidneys were damaged. They gave me steroids when I had kidney disease before I had chemotherapy</li> <li>• It messes up your organs but then they give it to you to treat disease – it’s a bit confusing</li> <li>• When I was younger I had a lot of organs messed up from steroids and I was on it for years and it caused me to have erythema multiple forms – started inside and then it caused the scarring</li> </ul>	
NG #3: 4/29/2019, 4 PM. 6 females. 2 white, 2 African American, 2 Asian. 36 votes.	
A. <b>Weight gain:</b>	9
<ul style="list-style-type: none"> <li>• That really bothers me</li> <li>• <i>It’s like an emotional roller coaster</i></li> </ul>	
B. <b>Bone loss:</b> Damage to bone	8
<ul style="list-style-type: none"> <li>• Spine collapsing, had to quit work because pain in my legs was horrendous and I couldn’t go upstairs</li> <li>○ <i>Bone density loss</i> <ul style="list-style-type: none"> <li>• <i>Every time I’m on it my bone density goes lower, we always measure it and it’s a concern. I’ve been on and off steroids since I was young</i></li> </ul> </li> <li>○ <i>Fractures</i></li> </ul>	
J. <b>Weakness:</b> Weakness in ligaments	4
<ul style="list-style-type: none"> <li>• Feel weaker and unstable, legs feel like sticks. They feel weaker and they’ll loosen when I go out</li> <li>○ <i>Tendon damage</i> <ul style="list-style-type: none"> <li>• <i>I blew out my Achilles tendon and the pain kept me up for 6 months</i></li> <li>• <i>Get instability mostly in hips – my heel starting bothering me and I was just crossing the street and fell and I didn’t know why</i></li> <li>• <i>Because of the steroids I had to elevate my legs in bed for 3 months because they didn’t want my skin to swell because my skin became very thin. It was crazy</i></li> </ul> </li> </ul>	
E. <b>Infection:</b> Lowers immune system	4
<ul style="list-style-type: none"> <li>○ <i>Frequent infections</i> <ul style="list-style-type: none"> <li>• <i>Jumped between UTI and yeast infections</i></li> <li>• <i>I have chronic bronchitis and pulmonary issues</i></li> </ul> </li> <li>○ <i>Infections</i></li> </ul>	
G. <b>Sleep disturbance:</b> Lack of sleep	2
<ul style="list-style-type: none"> <li>• When I’m on high doses of steroids, I get so hungry I need to wake up and eat every 3 hours. It wakes me up because my stomach is grumbling</li> </ul>	
J. <b>Weakness:</b> Muscle weakness	2
<ul style="list-style-type: none"> <li>• Was crossing the street and my leg just went out</li> <li>○ <i>Lack of strength</i> <ul style="list-style-type: none"> <li>• <i>I fell off the toilet and couldn’t get off the floor so I had to call my doorman to pick me up and put me on the couch</i></li> </ul> </li> </ul>	

K. <b>Other:</b> High sugar	2
D. <b>Damaged organs:</b> Bloating	2
○ <i>Stomach irritation</i>	
● <i>I cannot sleep flat; it causes a lot of stomach problems</i>	
● <i>When you have to take something for your damaged organs. Steroids adversely affects your bones</i>	
○ <i>Stomach problems</i>	
K. <b>Other:</b> Skin becomes very thin	1
● <i>It's very easy to break and when it does it won't heal</i>	
C. <b>Physical appearance:</b> My face – along with weight gain; moon face	1
● <i>When I go to church, they see me weekly, not every day and people will say oh your face looks puffy and it gets to me</i>	
○ <i>Puffy face</i>	
○ <i>Round face</i>	
K. <b>Other:</b> High cholesterol, high sugar, high blood pressure	1
● <i>Had to take Lipitor and all that</i>	
NG #4: 5/7/2019, 4:30PM. 7 females. 2 white, 3 African American, 2 Asian. 42 votes.	
B. <b>Bone loss:</b> Bad for osteoporosis	17
● <i>I have osteoporosis</i>	
○ <i>Bone loss/bone damage</i>	
● <i>For me it's AVN. I'm 27 and I'm asking why do I have this and its because I've been taking it for 10 years. And I go to the gym a lot so what's going to happen at 65</i>	
● <i>I had to have a double hip replacement</i>	
● <i>That's what makes me not want to take it – it's supposed to make me feel better, but its also destroying my bones</i>	
○ <i>AVN and resulting impact on walking</i>	
● <i>Can't go to the gym</i>	
● <i>I can't do anything on that leg</i>	
● <i>Confusing because with AVN its painful but I'm told to workout everyday</i>	
● <i>For a long time I couldn't move and for years I was on crutches</i>	
H. <b>Psychological:</b> Causes depression, mood instability	8
● <i>When I first started taking it caused mood instability – I started taking it when I was young and I didn't realize it was medicine that was causing mood instability so I went on mood stabilizers. I always thought it was me; but then I realized it was the steroids. It's a big one</i>	
● <i>It makes you angry</i>	
○ <i>Angry</i>	
○ <i>Irritability</i>	
● <i>Steroids make me feel like I'm going crazy, because my mom would always ask me why are you angry and I would just say because I am I don't know</i>	
○ <i>Bad mood</i>	
○ <i>Lack of concentration</i>	
○ <i>Scatter brain</i>	

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○ <i>Anxiety</i>	
• <i>Sometimes I get really anxious</i>	
• <i>Sometimes you don't know if its disease activity or medicine</i>	
<b>I. Dependence</b>	8
○ <i>Addictive</i>	
○ <i>Dangerous to just stop you have to wean off of it</i>	
○ <i>Instability to taper</i>	
• <i>Without some sort of adrenal crash or steroid fatigue</i>	
• <i>Takes a long time to taper</i>	
• <i>I was taking up to 80 mg</i>	
<b>A. Weight gain:</b>	3
• <i>First time I was sick and started taking I went up to 155 pounds from 140 – it happened really fast</i>	
○ <i>Moon face</i>	
○ <i>Causes an increase of appetite/over eating</i>	
<b>K. Other: Teeth problems: cavities</b>	2
• <i>I take good care of my teeth but the steroids can eat away at your teeth. I didn't know it until they told me. I had to pay for a crown and if I didn't have any money I'd just not have a tooth</i>	
<b>G. Sleep disturbance: Steroid fatigue</b>	2
• <i>With myositis, whatever blood test they do, I was stable and my numbers were going down but I was still so tired. My rheumatologist said that there's this thing called steroid fatigue and that it can have that kind of effect on your body and that was when I was on a higher dose</i>	
<b>H. Psychological: Uncomfortable with myself</b>	1
• <i>Shaky, on edge – my regular doctor put me on 20 mg for strep throat. And I didn't want to take it. One time I just took 20 mg and he told me to take another one in the afternoon and I felt so bad. I was shaking, especially for strep throat I could have survived through it – will never do it again</i>	
• <i>Thought I was the only person who understood. I was going through it by myself – thought it was just me</i>	
<b>K. Other: Compatibility with other drugs</b>	1
<b>NG #5: 5/9/2019, 4:30PM. 3 females, 2 white, 1 African American. 18 votes.</b>	
<b>F. Eye Problems: Eyes</b>	3
○ <i>It effects your eyes</i>	
• <i>If you have problems being on prednisone it is really not a good thing. When I went to a lower dosage the pressure in my eyes grew. If I go to a high dose and stay on it the pressure goes up. It's not glaucoma yet</i>	
○ <i>Glaucoma</i>	
• <i>Didn't change with lower doses.</i>	
• <i>My doctors told me that if the steroids had that effect on me than I would have gotten it anyways</i>	
<b>H. Psychological: Mental stress</b>	3
• <i>You're viewed as old. You're a different person.</i>	

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<ul style="list-style-type: none"> <li>• Your social life gets affected by it. You're not able to make friends because of steroid side effects. I don't have a lot of friends in my life because steroids might be the main cause and I do blame steroids for it</li> <li>• My height and weight gain makes you not look good, not look pretty. Your self-image goes down. I missed out on my social life because of it took steroids from age 4 to 18</li> <li>• Mental stress makes you not a normal person</li> </ul>	3
<b>B. Bone loss:</b>	3
<ul style="list-style-type: none"> <li>• Need to take calcium</li> </ul>	
<b>K. Other: Height</b>	2
<ul style="list-style-type: none"> <li>• I was 4 when I started taking the steroids and now I'm 25. It's the main thing that has affected my life</li> </ul>	
<b>G. Sleep disturbance: Fatigue</b>	2
<ul style="list-style-type: none"> <li>• In my life I had school, college and doctors that's it I had to focus more on my studies than a regular person. It was hard for me to focus on stuff so it took me longer to study.</li> </ul>	
<b>C. Physical appearance: Hirsutism (hair growth)</b>	2
<ul style="list-style-type: none"> <li>• I got a mustache and what started to look like a beard and I really want my mustache to go away. My doctor had to take me off because I was getting too many side effects</li> </ul>	
<b>A. Weight gain:</b>	1
<ul style="list-style-type: none"> <li>○ <i>Hard to lose weight</i></li> </ul>	
<b>A. Weight gain: Increases appetite.</b>	1
<ul style="list-style-type: none"> <li>• Even when you just ate something you think, I just ate something I shouldn't be hungry and sometimes I'm just snacking and I know I'm not hungry. At some point I need to find a medium here. It put weight on me and trying to get the weight off is crazy</li> <li>• I was young when I was taking them and my mom would prepare food for me and I would ask for more. It took me 8 years to take the weight off</li> <li>• I have to do therapy to function. Even when I'm in therapy I think what am I going to eat</li> <li>• It makes you eat and you're thinking about eating all the time</li> <li>• Compulsive eating – I had to use gum to control my appetite</li> <li>• It requires you to eat a lot of sweet stuff</li> <li>○ <i>Always thinking about food/eating</i></li> <li>○ <i>Eating while not hungry</i> <ul style="list-style-type: none"> <li>• <i>People in my old support group</i> would say that the appetite didn't affect them, but it affected me</li> <li>• Prednisone can be your good friend and your bad friend</li> </ul> </li> </ul>	
<b>K. Other: Hard to study/concentrate</b>	1
<ul style="list-style-type: none"> <li>○ <i>Effects your memory</i> <ul style="list-style-type: none"> <li>• <i>It's called the lupus fog</i> and you're talking and then forget what you're saying</li> <li>• I had to go on disability and I didn't have a choice and needed to get over</li> </ul> </li> </ul>	

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for having the disability label and I needed to go back to college and  
wanted to go back and get my masters and when I went off the meloxicam  
I was able to focus

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Total: 126 votes

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NG = Nominal group. AVN = Avascular necrosis.

A = Weight gain; B = Bone loss; C = Physical appearance; D = Damaged organs; E = Infection; F =  
Eye Problems; G = Sleep disturbance; H = Psychological Effects; I = Dependence; J = Weakness; K  
= Other

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