Layman's version of "Patient and rheumatologist perspectives on glucocorticoids: an exercise to improve the implementation of the European League Against rheumatism (EULAR) recommendations on the management of systematic glucocorticoid therapy in rheumatic diseases"

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Introduction

Glucocorticoids (GCs) have been widely used for decades, and in low-dose use, GCs are relatively safe to use. There are discussions about risks and benefits, which has led to the formation of an European Task Force on GC therapy. The Task Force set up by EULAR (European League Against Rheumatism), developed evidence based recommendations on the management of systematic low-dose to high-dose GC therapy in rheumatic diseases.

Patients are also aware of the benefits and risks of GC therapy. Serious concerns about adverse events because of GCs sometimes even leads patients to refuse to take GC treatment. (Adverse events are negative or harmful effects of medication. These can occur next to a beneficial effect that is aimed for when using medication). Furthermore, many patients feel that they frequently need to defend themselves towards family, friends and doctors (except the prescribing rheumatologist) for their use of GCs; they do so by explaining the medical need for these drugs.

Therefore, in this study, two topics were studied. The first topic was to explore the perspectives among patients and rheumatologists on glucocorticoids (GC), such as prednisolone. The second topic was to study how the recommendations on the management of systematic GC therapy were perceived and to rank these recommendations for importance.

The study

Rheumatologists from 8 different countries and patients from 5 different countries, who had experience with GCs, came together and discussed the positive and negative aspects of GC therapy. They were also asked to rank possible adverse events. Furthermore, they were asked to evaluate the published recommendations on the management of systematic GC therapy, published by EULAR (European League Against Rheumatism). This evaluation was meant to improve the implementation of these recommendations. The reports from these meetings were discussed during an international forum of the experts and the patient participants who had formulated these EULAR recommendations.

Ranking adverse events

Out of a list of 37 possible adverse effects of GC treatment, both the rheumatologists and the patients, chose osteoporosis, diabetes and cardiovascular diseases within the five most worrisome adverse events. Differences in scoring of both groups were found for some adverse events, such as: patients scored renal dysfunction, fatigue, palpitations and dyspnoea as more worrisome compared to the rheumatologists. Patients scored very rare adverse events to be worrisome, even without knowledge of the chance of occurence. The rheumatologists scored diabetes, osteoporosis, hypertension, infections and atherosclerosis as more worrisome than the patients. The rheumatologists scored serious adverse events that rarely occur, not as worrisome.

Evaluation of the "EULAR recommendations on the management of systematic GC therapy in rheumatic diseases"

The patients and the rheumatologists were asked to evaluate each of the ten recommendations (see below) by giving a rating scale from 0 (no agreement) to 10 (total agreement). There was agreement with most of the recommendations. The mean total score for all recommendations was 8.1 for patients and 7.8 for the rheumatologists. The three recommendations (as described below) that received the lowest scores and most criticism from both groups are: recommendation 1C (7.0), recommendation 8 (7.7) and recommendation 9 (5.4)

Recommendation 1C: "If GCs are to be used for a more prolonged period of time, a "GC card" is to be issued to every patient, with the date of commencement of treatment, the intial dosage and the subsequent reductions and maintenance regimens."

Athough a GC card is routinely issued in the UK, other countries doubted the feasibility of implementing this recommendation: the rheumatologists noted that issuing a GC card and keeping it updated would be time consuming, thus difficult to implement. The opinions of patients varied: some preferred to have such a card for emergency situations, especially when travelling, possibly even for all medications, while others did not see the value of it.

Suggestion to improve recommendation 1C: Good patient education and doctor information about the purpose of GC cards and discussion with pharmacists on how to increase feasibility could improve the use of GC cards.

Recommendation 8: "All patients on GC therapy for longer than 1 month, who will undergo surgery, need perioperative management with adequate GC replacement to overcome potential adrenal insufficiency."

Most rheumatologists agreed with this recommendation, although many of them mentioned the lack of scientific evidence and the need for evidence based peri-operative GC schemes (i.e. the way GCs can be prescribed in the period before the patient undergoes surgery). The rheumatologists discussed whether there would be an increased risk of impairment of wound healing and infections at the use of low dose GCs. The patients, however, mentioned the advantage of taking additional GCs in the period after the surgery, since it improved their disease control and recovery.

Suggestion to improve recommendation 8: If there is a risk of adrenal insufficiency, the benefit of adequate GC replacement seems to outweigh the risk. Whether improved perioperative disease control (using GCs) aids postoperative recovery requires further investigation.

Recommendation 9: "GCs during pregnancy have no additional risk for mother and child."

This recommendation was scored lowest of all by patients and rheumatologists. Patients noted their lack of knowledge and were suspicious towards the use of any medication during pregnancy. Rheumatologists disagreed with this recommendation because in their opinion GCs are not completely safe during pregnancy and safety depends on dosage. They felt that only if necessary GCs should be prescribed during pregnancy, and that GCs in general are associated with lower risks compared to other antirheumatic medication during pregnancy.

Suggestion to improve recommendation 9: Available research shows that rheumatic diseases can increase the risk of pregnancy problems and that GC therapy, given in low-dose to medium-dose, has no proven additional risk.

It is evident from this study that the views of patients and rheumatologists should be included early in the process of formulating recommendations, in order to identify important topics and to enhance implementation.

European League Against Rheumatism (EULAR) evidence-based recommendations on systematic glucocorticoid therapy in rheumatic diseases

1 a The adverse effects of glucocorticoid therapy should be considered and discussed with the patient before glucocorticoid therapy is started

1 b This advice should be reinforced by giving information regarding glucocorticoid management

1 c If glucocorticoids are to be used for a more prolonged period of time, a ‘‘glucocorticoid card’’ is to be issued to every patient, with the date of commencement of treatment, the initial dosage and the subsequent reductions and maintenance regimens

2 a Initial dose, dose reduction and long-term dosing depend on the underlying rheumatic disease, disease activity, risk factors and individual responsiveness of the patient

2 b Timing may be important, with respect to the circadian rhythm of both the disease and the natural secretion of glucocorticoids

3 When it is decided to start glucocorticoid treatment, comorbidities and risk factors for adverse effects should be evaluated and treated where indicated; these include hypertension, diabetes, peptic ulcer, recent fractures, presence of cataract or glaucoma, presence of (chronic) infections, dyslipidaemia and comedication with non-steroidal anti-inflammatory drugs

4 For prolonged treatment, the glucocorticoid dosage should be kept to a minimum, and a glucocorticoid taper should be attempted in case of remission or low disease activity; the reasons to continue glucocorticoid therapy should be regularly checked

5 During treatment, patients should be monitored for body weight, blood pressure, peripheral oedema, cardiac insufficiency, serum lipids, blood and/or urine glucose and ocular pressure depending on individual patient’s risk, glucocorticoid dose and duration

6a If a patient is started on prednisone >7.5 mg daily and continues on prednisone for more than 3 months, calcium and vitamin D supplementation should be prescribed

6b Antiresorptive therapy with bisphosphonates to reduce the risk of glucocorticoid-induced osteoporosis should be based on risk factors, including bone-mineral density measurement

7 Patients treated with glucocorticoids and concomitant non-steroidal anti-inflammatory drugs should be given appropriate gastro-protective medication, such as proton pump inhibitors or misoprostol, or alternatively could switch to a cyclo-oxygenase-2 selective inhibitor

8 All patients on glucocorticoid therapy for longer than 1 month, who will undergo surgery, need perioperative management with adequate glucocorticoid replacement to overcome potential adrenal insufficiency

9 Glucocorticoids during pregnancy have no additional risk for mother and child

10 Children receiving glucocorticoids should be checked regularly for linear growth and considered for growth-hormone replacement in case of growth impairment