The median reported current daily dose of prednisolone was 15 mg and median treatment duration was 5.3 years at the time of survey completion. Females were more likely to stay on GCs for longer than males (5.4 vs 4.7 years, $p=0.046$).

Table 1. Mean severity and frequency for each adverse effect.

	All respondents (n=122)	Male (n=26)	Female (n=96)	<60 years (n=89)	≥60 years (n=33)
Moon face	3.3 (1.9)	2 (2.1)*	3.6 (1.7)*	3.5 (1.8)	2.7 (2)
Weight gain	3.4 (1.7)	3.1 (1.6)	3.4 (1.8)	3.5 (1.7)	3.1 (1.9)
Acne	1.1 (1.5)	1 (1.5)	1.2 (1.6)	1.3 (1.6)	0.7 (1.2)
Hair loss	2 (1.8)	0.8 (1.4)*	2.4 (1.8)*	2.2 (1.8)**	1.5 (1.9)**
Facial hair	2.1 (1.8)	0.7 (1.3)*	2.5 (1.8)*	2.3 (1.8)	1.7 (1.8)
Thin skin	2.2 (1.9)	1.8 (2)	2.3 (1.8)	2.2 (1.9)	2.3 (1.9)
Bruising	2.2 (1.7)	2.1 (1.9)	2.2 (1.7)	2.2 (1.7)	2 (1.9)
Stretch marks	1.3 (1.9)	0.9 (1.5)	1.4 (1.8)	1.5 (1.9)**	0.6 (1.2)**
Nausea	1.4 (1.7)	1.6 (1.8)	1.4 (1.6)	1.5 (1.6)	1.2 (1.7)
Heartburn	1.9 (1.8)	1.8 (1.9)	1.9 (1.8)	2 (1.8)	1.5 (1.8)
Hunger	2.8 (1.7)	2.2 (1.9)*	3 (1.6)*	3 (1.6)	2.4 (2)
Mood swings	2.7 (1.6)	2.1 (1.8)	2.7 (1.5)	2.8 (1.6)	2.6 (1.6)
Sleep disturbances	3.1 (1.5)	2.9 (1.7)	3.2 (1.4)	3.2 (1.5)	3 (1.5)
Cataracts	0.6 (1.3)	1.1 (1.8)	0.5 (1.1)	0.5 (1.2)	1 (1.6)
Glaucoma	0.4 (1.1)	0.6 (1.5)	0.3 (0.9)	0.4 (1)	0.4 (1)
Hypertension	1.6 (1.7)	1.8 (1.7)	1.5 (1.7)	1.5 (1.7)	1.8 (1.8)
Diabetes	0.8 (1.6)	1 (1.6)	0.8 (1.6)	0.7 (1.5)	1 (1.8)
Water retention	2.2 (1.7)	1.7 (1.6)	2.3 (1.8)	2.3 (1.8)	1.9 (1.6)
Infections	2.2 (1.8)	2.2 (1.7)	2.2 (1.7)	2.2 (1.7)	2.1 (1.7)
Fractures	0.5 (1.1)	0.5 (1.2)	0.5 (1.1)	0.5 (1.6)	0.5 (1.1)

Mean severity on a Likert scale (0-5), mean (SD); * $p<0.05$, male vs female; ** $p<0.05$, <60 years vs ≥60 years.

Frequency (number of patients reporting adverse effect as present), heatmap: White (0-33%), light grey (33-66%), dark grey (66-100%).

The mean number of reported AEs to GC treatment per patient was 12 (SD 5). Female respondents reported a greater number of AEs compared to males (12.6 vs 10.1, $p=0.019$). The three most commonly experienced AEs were: sleep disturbance (93%), mood swings (86%) and weight gain (86%). Only 54% of respondents agreed that the information given about the potential risks of GC treatment was adequate. Mean severity and frequency of AEs is represented in table 1.

Conclusion: Adverse effects are common, and those rated more severe by patients were physical and behavioural (such as weight gain or sleep disturbance). Female patients reported more severe AEs compared to men.

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SAT0632-HPR PATIENTS VIEW ON CONSULTATION IN OUTPATIENT CLINIC – FROM SATISFACTION TO DEMAND OF GUIDANCE INTO MORE SELF-MANAGEMENT

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Background: Patients with rheumatic diseases, routinely consult the outpatient clinic 1-2 times a year to see their rheumatologist. Many of the patients also attend nurse-led consultations to receive instructions, regarding treatment in association to their intravenous treatment, or DMARD dispensing in the clinic. As clinicians we have an assumption of what the "good practice" is in relation to the patients, but we have little insight, into the patients' own experience and satisfaction.

Objectives: To investigate the patients views on the level of information, and their experience and satisfaction with the doctor and nurse-led consultations in the outpatient clinic.

Methods: The approach of the survey was both quantitative and qualitative. A questionnaire was designed with four questions on a matrix scale concerning their information level on their disease/symptoms; their treatment; if they had received written material and if so, it's value; and their possibility to talk about subjects that matters for them during consultations. To gain a qualitative approach with focus on the patients' experiences and comments, every question was constructed with space for comments. Comments were transcribed, indexed, analysed, and thematically divided. The inclusion of patients were all patients visiting the clinic within a specific week in January 2019.

Results: The results from the four questions, are shown in the figures below, measured in percentage. In total, 283 participated (response rate 60%).

Four themes covered from the analysis of patients' comments. "Seeking own answers", "Own coping – effort", "Conversation with doctor/nurse" and "Treatment/medication". Comments revealed many descriptions and stories of patients, showered with all types of suggestions of taking control or managing the disease by them self, from their family or media. It also revealed their interest in discussing, these subjects and matters with the doctor/nurse, without being rejected. The feeling of rejection resulted in some patients trying other treatments or introducing changes in their lifestyle, without involving the doctor. The patients also called for more knowledge about physical training, and not only medical treatment.

Conclusion: In general, the patients had a very positive perception towards the consultations, and the information from the outpatient clinic. Despite that, the themes indicated a pattern, that needs to be considered, so clinicians acknowledge the patients wish for guidance, besides the medical treatment. To support the patient, without leaving them with a feeling of being rejected, we need to consider how to articulate the subjects the patients are exposed to outside our clinic, so the patients feel free to inform or involve the clinic instead of being silent, in risk of counteracting the medical treatment.

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SAT0633-HPR AN EXPLORATION INTO THE CONVERSATIONS AROUND SEXUAL FUNCTIONING THAT MALES WITH SJÖGREN'S SYNDROME HAVE ON AN INTERNET FORUM.

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Background: Sjögren's Syndrome (SS) is an autoimmune rheumatic disease that targets secretion glands throughout the body, causing symptoms of oral, ocular and genital dryness (van de Merwe, 2010). A small body of literature has investigated the impact of SS on women's sexual functioning, however, no research currently exists that has explored this topic in males with SS. Gathering a snapshot of issues may prove difficult given the sensitivity of the topic. Therefore, data must be gathered from sources where individuals may have the confidence to talk openly. Research has shown that many patient groups turn to internet forums to discuss sensitive issues under the cloak of anonymity (White & Dorman, 2001). Analysing this source of data allows us to explore the conversations pertaining to sexual functioning that males with SS may not feel comfortable discussing in a traditional qualitative setting, and may be instrumental in guiding future intervention strategies.

Objectives: To explore the conversations around sexual functioning that male users with SS have on an internet forum.

Methods: A large publicly accessible internet forum that individuals with a diagnosis of SS used to discuss issues and share experiences with other users was selected. Thread names and post content were scraped using a web scraping tool, and posts identified as containing relevant keywords were exported into Excel. Braun & Clarke's (2006) thematic analysis was used to analyse post content.

Results: A total of 78 posts were identified as being pertinent to the topic of male sexual functioning. Conversations were predominately centred on symptom presence in the reproductive organs. Forum users discussed having fluctuating pain in the testicles, scrotum, groin, anus, and rectum. They also reported experiencing