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SAT0630-HPR

EFFECTS OF GOLIMUMAB ON WORK PRODUCTIVITY AMONG WORK-ACTIVE ANKYLOSING SPONDYLITIS, NON-RADIOGRAPHIC AXIAL SPONDYLOARTHRITIS AND PSORIATIC ARTHRITIS PATIENTS IN GREECE: THE 'GO-UP' STUDY

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Background: Golimumab is a tumor necrosis inhibitor (TNFi) approved for the treatment of axial SpA (axSpA) and psoriatic arthritis (PsA), both falling under the Spondyloarthritis (SpA) domain. Real-world data regarding its effect on work productivity (WP) and activity impairment (AI) are limited

Objectives: To assess the impact of golimumab on WP and AI over 12 months of treatment in patients with SpA, overall, and in the axSpA and PsA subpopulations

Methods: A 12-month non-interventional, multicenter, prospective study performed in the routine clinical care. Data were collected at baseline (BL: prior to treatment onset), 3, 6 and 12 months. Adult work-active consented patients with axSpA [ankylosing spondylitis (AS) or non-radiographic axSpA (nr-axSpA)] or PsA, newly initiated on golimumab as per approved label, were consecutively enrolled by 20 sites. Patients prior in >1 biologic agent, or switched from another TNFi due to primary non-response or safety were excluded. WP and AI was assessed with the Work Productivity and Activity Impairment: Specific Health Problem (WPAI:SHP) instrument

Results: Between Apr-2017 and May-2018, 121 (51: PsA, 70: axSpA) eligible patients (mean age: 45.4 years; 49.6% males; 69.0% overweight/obese; median disease duration: 11.3 months), (Figure 1), were enrolled. Median study duration participation: 11.9 months. Overall, 60.3% of the patients had previously received disease-modifying antirheumatic drugs and 16.5% biologics. At BL, the mean (standard deviation: SD) DAS28-ESR of the SpA population and PsA and axSpA subpopulations was 4.0 (1.3), 4.5 (1.2), and 3.6 (1.2), while the mean (SD) BASDAI score of patients with axSpA was 5.6 (1.9). At BL 94.1 and 96.7% of the SpA population reported WP loss and AI due to their SpA respectively, and at 3 months 87.3, and 88.0% respectively. In SpA population, the median BL WP loss and AI were 70.0% and 65.0% and decreased by a median of 31.4% and 40.0% at 3 months, by 44.2% and 40.0% at 6 months and by 50.0% and 50.0% at 12 months, respectively (Table 1). Improvements in WP loss and AI were noted in patients with PsA, axSpA, AS and nr-axSpA (Table 1). 12-month golimumab retention rate: 91.7%. No new safety signals emerged

Table 1. Decreases from BL at 3, 6 and at 12 months in WP loss and overall AI with the WPAI:SHP instrument

	WP loss (%)			AI (%)		
	Decrease from BL, median (n)			Decrease from BL, median (n)		
	3 months	6 months	12 months	3 months	6 months	12 months
Overall SpA population^a	31.4 ^a (n=102)	44.2 ^a (n=94)	50.0 ^a (n=87)	40.0 ^a (n=107)	40.0 ^a (n=101)	50.0 ^a (n=92)
PsA	31.4 ^b (n=46)	51.4 ^a (n=42)	53.6 ^a (n=40)	40.0 ^a (n=47)	50.0 ^a (n=44)	60.0 ^a (n=40)
axSpA	33.0 ^b (n=56)	30.4 ^b (n=52)	45.5 ^b (n=47)	40.0 ^a (n=60)	40.0 ^b (n=57)	40.0 ^b (n=52)
AS^c	25.1 (n=35)	29.9 (n=32)	39.8 (n=29)	20.0 (n=39)	30.0 (n=37)	30.0 (n=34)
nr-axSpA^c	47.4 (n=21)	55.4 (n=20)	53.2 (n=18)	50.0 (n=21)	55.0 (n=20)	50.0 (n=18)

^aSignificant decreases (p<0.001; Wilcoxon signed-ranked test)

^bSignificant decreases (p<0.001; t-test)

^cStatistical significance of the change from baseline was not examined due to the small observations' number

Conclusion: Patients in the SpA population and axSpA and PsA subpopulations treated with golimumab in a routine care setting experienced significant improvements in work productivity and daily activities at 3, 6 and 12 months after treatment initiation

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Figure 1. Study flow-chart and patient disposition per spondyloarthritis indication

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SAT0631-HPR

WHEN CAN I STOP MY STEROIDS? THE PATIENT PERSPECTIVE ON GLUCOCORTICOID USAGE IN ADULT INFLAMMATORY MYOPATHY

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Background: Glucocorticoids (GC) are long established as a first line treatment in patients with idiopathic inflammatory myopathy (IIM), in which high dose, long duration treatment is often required. GC usage is associated with a wide range of adverse effects (AEs). The patient perspective on the risks and benefits of GCs is not well studied and no prior studies assesses this issue in IIM patients (1).

Objectives: To describe the perspective of IIM patients on GC treatment.

Methods: We deployed an online survey distributed using the Myositis UK page on Healthunlocked.com, an online social network for health, with approximately 450 patients registered. Patients with diagnosed IIM were invited to take part on an anonymised basis. Respondents were asked to grade the severity on a Likert scale (1 to 5) of all AEs experienced in relation to GC. Additionally, respondents were asked to write about their concerns and to rate their overall experience with GC treatment.

Results: In total, 122 completed surveys were received. Forty five percent (55/122) of respondents had dermatomyositis, 27% (33/122) polymyositis, 10% (12/122) anti-synthetase syndrome, 18% (22/122) other inflammatory myopathies. Seventy-nine percent (96/122) of respondents were female and the mean age overall was 50 years (SD [standard deviation] 14).

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 (1.7)	2.2 (1.8)	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