Treat-to-target and shared decision-making in systemic lupus erythematosus from the patients' perspective: results from an international patient survey

J. Mucke[1,2], D.T. Pencheva[3,4], A.R. Parra Sánchez[5,6], K. Cramer[7],
M. Schneider[1,2], I.E.M. Bultink[5,6]

*[1]Department of Rheumatology, University Hospital Düsseldorf, Medical Faculty of Heinrich Heine University, Düsseldorf, Germany; [2]Hiller Research Center, University Hospital Düsseldorf, Medical Faculty of Heinrich Heine University, Düsseldorf, Germany;
[3]Department of Physiology and Pathophysiology, Medical University of Sofia, Sofia, Bulgaria;
[4]Department of Rheumatology, University Clinical Hospital St. Ivan Rilski, Sofia, Bulgaria;
[5]Department of Rheumatology, Amsterdam Rheumatology and Immunology Center, Amsterdam University Medical Center, Amsterdam, The Netherlands;
[6]Amsterdam Institute for Infection and Immunity, Amsterdam, The Netherlands;
[7]Patient Research Partner, Amsterdam, The Netherlands.*

Abstract

Objective

Treat-to-target (T2T) is being recognised as a promising concept to significantly improve the outcomes of patients with systemic lupus erythematosus (SLE). Despite its success being closely tied to patients' involvement, the patients' perspective regarding T2T has not been evaluated. We aimed to investigate patients' attitude towards T2T and their involvement in treatment decisions.

Methods

We designed a 13-question online survey on T2T, examining acceptance, willingness to participate in T2T trials, and potential obstacles. This was distributed amongst Dutch, Austrian, German, and Bulgarian patient organisations.

Results

In total, 863 patients participated of whom 48.4% reported being in remission, while 13% were uncertain about their remission status. Regarding shared decision-making, 62.1% reported being somewhat fully involved in treatment decisions, while 20.7% felt uninvolved. Shared decision-making was associated with disease duration, Dutch origin and satisfaction with treatment and remission. As for satisfaction with their health status, 56.2% were somewhat fully satisfied, while 29.3% were unsatisfied. 65.5% were satisfied with their treatment, 14.8% were not. Leading treatment goals were quality of life (QoL) normalisation (37.4%), organ damage prevention (24.6%) and absence of disease activity (22.6%). T2T was mainly seen positive with additional doctors' visits and initiation of new immunosuppressive drugs as potential disadvantages.

Conclusion

T2T was perceived as beneficial with improvement of QoL as the most important treatment goal and the possibility of additional doctors' visits and initiation of new immunosuppressive agents as potential drawbacks. Patients unsatisfied with their health status and treatment may benefit from greater involvement in treatment decisions.

Key words

systemic lupus erythematosus, health status, remission, quality of life, disease activity

Clinical and Experimental Rheumatology 2024; **42**: 1744-1749.

Johanna Mucke, MD
Daliya T. Pencheva, MD
Agner R. Parra Sánchez, MD
Kyra Cramer
Matthias Schneider, MD
Irene E.M. Bultink, MD

Please address correspondence to:
Johanna Mucke
Department of Rheumatology,
University Hospital Düsseldorf,
Moorenstraße 5,
40225 Düsseldorf, Germany.
E-mail:
johanna.mucke@med.uni-duesseldorf.de
ORCID iD: 0000-0001-8915-7837

Received on January 12, 2024; accepted in revised form on February 28, 2024.

Funding: J. Mucke received funding from the Training Bursary Programme of the European Lupus Society (SLEuro) to carry out the work described in this manuscript.

Competing interests: J. Mucke and M. Schneider received consulting fees and honoraria for presentations from AstraZeneca, GSK and BMS, and declare a research grant from GSK. I.E.M. Bultink received consulting fees and honoraria for presentations from AstraZeneca, GSK, UCB, Eli Lilly, Roche and Sanofi Genzyme.
The other authors have declared no competing interests.

Introduction

Substantial strides in systemic lupus erythematosus (SLE) management over the past few decades have led to a decrease in mortality rates. However, an SLE diagnosis is still profoundly correlated with an elevated disease burden, diminished quality of life (QoL), and a higher mortality rate (1, 2). Thus, there is a pressing need for new therapeutic options and to devise new therapeutic strategies to enhance the prognosis of patients affected by SLE.

Current recommendations name Treat-to-Target (T2T) as the promising treatment strategy in SLE (3), a concept that has already proven effective in managing diseases such as rheumatoid arthritis and psoriatic arthritis, leading to enhanced QoL, reduced disease burden and prevention of comorbidities (4-7).

The primary objective of this method is to prevent extended periods of inefficient treatment and shorten the time until remission, with the aim to improve the patient's outcome (8). For SLE patients, periods of remission are associated with improved QoL, reduced risk of further damage and comorbidities, lower dosages of glucocorticoids, and decreased mortality rates (9). Typically, the longer the duration of remission, the more significant the beneficial effect.

Implementing T2T in SLE treatment necessitates a well-defined target and with the definition of remission in SLE (DORIS) and lupus low disease activity state in SLE (LLDAS), easily assessable targets are available for the management of SLE (10, 11). Both targets still require validation through prospective randomised controlled trials, and neither of them takes into account the concerns expressed by patients, such as the desire to minimise side effects of medications and enhance the patients' QoL (12).

Therefore, a vital precondition for a successful T2T approach is the shared decision-making (SDM) process between patients and physicians. In the context of SLE, adherence to treatment is challenging even without a T2T approach, often due to concerns about harmful side effects and long-term organ damage associated with medication use as well as disagreement about the need for treatment (13, 14). Therefore, patient education and empowerment are essential to emphasise aspects such as the importance of treatment, reducing glucocorticoid use and the benefits of adopting a T2T strategy with remission as target and thus improve adherence. As per the European Alliance of Associations for Rheumatology (EULAR) recommendations on rheumatoid arthritis, SDM should encompass all aspects of treatment including disease education, risk communication, decisions on therapeutic targets, development of a management plan, and discussions on the benefits and risks of individual therapies (15, 16).

T2T requires a strong commitment from both patients and healthcare providers. Hence, it is important to identify factors that may hinder the successful implementation of T2T on both sides, such as shortage of time, the need for frequent and precise assessments of disease activity through validated scoring methods, and both patient and physician preferences (17).

Given that the success of the T2T strategy is significantly hampered without active patient participation, we are set to assess SLE patients' attitudes towards the T2T approach. We aim to explore potential advantages and disadvantages, identify key treatment goals and assess challenging decisions that may arise throughout the process.

Methods

The study was approved by the local ethics committee of the Medical Faculty at Heinrich-Heine-University Duesseldorf and the local ethics committee of Amsterdam University Medical Center and conformed to the provisions of the Declaration of Helsinki

Survey design

A survey of 13 questions on T2T in SLE, its acceptance, the need and willingness to participate in a T2T trial and possible obstacles for T2T was designed in a team of two rheumatologists (JM, IEMB) and a patient research partner (KC) in German language (online Supplementary Data S1). Translation into Dutch (Suppl. Data S2) and Bulgarian (Suppl. Data S3)

Table I. Demographics.

	Total n (%)	Netherlands n (%)	Germany n (%)	Austria n (%)	Bulgaria n (%)
Female	805 (93.3)	282 (89.2)	257 (94.8)	42 (95.5)	224 (96.6)
Male	58 (6.7)	34 (10.8)	14 (5.2)	2 (4.5)	8 (3.4)
Age					
<30 years	76 (8.8)	15 (4.7)	27 (10.0)	7 (15.9)	27 (11.6)
30-35 years	102 (11.8)	25 (7.9)	39 (14.4)	7 (15.9)	31 (13.4)
36-40 years	94 (10.9)	21 (6.6)	29 (10.7)	5 (11.4)	39 (16.8)
41-50 years	228 (26.4)	65 (20.6)	69 (25.5)	10 (22.7)	84 (36.2)
51-60 years	224 (26.0)	99 (31.3)	73 (26.9)	12 (27.3)	40 (17.2)
>60 years	139 (16.1)	91 (28.8)	34 (12.5)	3 (6.8)	11 (4.7)
Disease duration					
<1 year	43 (5.0)	13 (4.1)	18 (6.6)	5 (11.4)	7 (3.0)
1-2 years	64 (7.4)	18 (5.7)	17 (6.3)	6 (13.6)	23 (9.9)
3-5 years	135 (15.6)	39 (12.3)	42 (15.5)	9 (20.5)	45 (19.4)
6-10 years	148 (17.1)	30 (9.5)	48 (17.7)	9 (20.5)	61 (26.3)
>10 years	473 (54.8)	216 (68.4)	146 (53.9)	15 (34.1)	96 (41.4)

and back-translation was performed by the study personnel and the help of two bilingual rheumatologists. Foundation for the questionnaire was a literature screening in PubMed on factors important for patients in SDM processes, reasons for non-adherence and challenges of T2T (18-22). Beyond demographic data, the survey comprised questions on the patients' satisfaction with the current treatment, health status and remission status, the patient's treatment goal and his/her current involvement in treatment decisions. Further, participants were asked for their most difficult treatment decisions in an SDM setting. A set of possible scenarios in a T2T-setting were presented and rated as *advantage, disadvantage* or *neutral* by the participants.

Survey distribution

The survey was distributed among members of the SLE patient organisations of the Netherlands (NL), Austria (AU), Germany (GE) and Bulgaria (BG) via newsletter (GE, AU, and BG), personal invitation (NL) and a closed Facebook group (BG). All patients had a self-reported physician's diagnosis of SLE.

Statistical analysis

The data were analysed using the statistical software programme R version 3.5.0 (The R Foundation for Statistical Computing) with a significance level of α=0.05, and are presented as numbers and percentages or medians and 25th-75th percentile interquartile range (IQR) where appropriate. Regression analyses were performed to assess factors influencing patients' satisfaction. The results are reported as point estimates with 95% confidence intervals and *p*-values. Only complete datasets were analysed.

Results

Demographic data

A total of 863 patients (n=316 NL, n=271 GE, n=232 BG, n=44 AU), 93.3% female, 52.2% aged 41-60 years with a self-declared diagnosis of SLE completed the questionnaire. For the demographic data see Table I.

Remission rates and satisfaction with the current health status

Of all respondents, 48.4% declared they were currently in remission, 13% did not know if they were in remission and 38.6% reported that they were not. Regarding satisfaction with their current health status, 56.2% were somewhat to completely satisfied while 29.3% were not at all or hardly satisfied. 65.5% were satisfied with their current therapeutic treatment, while 14.8% where not at all or hardly satisfied with their treatment. Longer disease duration and Dutch origin were associated with higher satisfaction of both health status (disease duration: estimate 0.15, 95%CI 0.09–0.22, $p<0.001$; Dutch origin: estimate 0.42, 95%CI 0.27–0.61, $p<0.001$) and therapeutic treatment (disease duration: estimate 0.11, 95%CI 0.05–0.17, $p<0.001$; Dutch origin: estimate 0.58, 95%CI 0.40–0.75, $p<0.001$).

Important treatment goals

As the most important treatment goal, normalisation of QoL was chosen most frequently (37.4%) followed by prevention of organ damage (24.6%) and the absence of disease activity (22.6 %). (Fig. 1)

Shared decision-making

Regarding shared decision-making (SDM), the majority reported being somewhat to completely involved in treatment decisions (62.1%) while 20.7% were hardly or not at all involved. Univariate analyses revealed an association of greater involvement in treatment decisions (SDM) with Dutch origin, longer disease duration, self-reported remission and higher satisfaction with health status and treatment decisions. In the multivariate analysis, this finding was confirmed for disease duration, Dutch origin, self-reported remission and satisfaction with treatment. (Table II)

Difficult decisions and perceived advantages and disadvantages of T2T

As most difficult decisions in T2T and SDM, respondents named the start of new SLE medication (37.9%) and changing medication while feeling good (39.4%). An increase in the dose of glucocorticoids to reach remission was difficult for 22.7%.

Possible consequences of a T2T approach were rated as advantage, disadvantage or neutral. Generally, most consequences were seen as advanta-

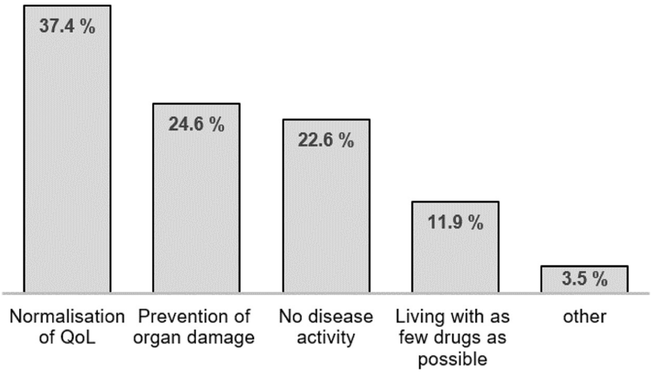

Fig. 1. Most important treatment goals of patients with systemic lupus erythematosus. QoL: quality of life.

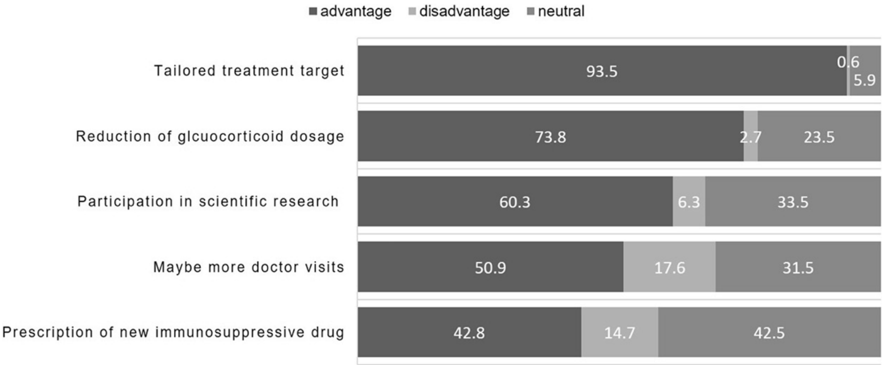

Fig. 2. Consequences of treat-to-target rated as advantage or disadvantage by patients with systemic lupus erythematosus in % of all respondents.

geous or neutral. More precisely, pursuing a tailored treatment target and the reduction of glucocorticoid dosage as well as possible participation in scientific research about T2T were mainly seen as an advantage of T2T. While additional doctor visits and the prescription of new immunosuppressive drugs were considered an advantage (50.9% and 42.8%, respectively) or neutral (31.5% and 42.5%) by most respondents, a substantial percentage perceived these consequences as a disadvantage (17.6% and 14.7%). (Fig. 2)

Discussion

In this survey, we evaluated the demand for a T2T strategy, its acceptance, and the perceived advantages and disadvantages of a T2T approach in a large international cohort of patients with SLE. The implementation of T2T requires commitment from both physicians and patients. Physicians must maintain focus on the treatment target, schedule regular visits, and be prepared to make more frequent treatment adjustments compared to conventional care protocols. At the same time, patients must be well-informed and possess a solid understanding of their disease and the T2T strategy to fully and actively participate in the T2T concept.

Overall, the prospect of participating in T2T was largely viewed as advantageous. No significant drawbacks were associated with the T2T concept, and as such, we anticipate a high level of willingness among patients to participate in T2T trials.

With respect to the different aspects of T2T, respondents were positive about the T2T idea and the tailored treatment, as well as the potential to reduce the glucocorticoid dose. Most respondents also perceived the likelihood of more frequent visits to the doctor and the prescription of a new immunosuppressive drug as benefits.

In patients who consider more frequent doctor visits and the prescription of a new immunosuppressive drug as a potential disadvantage (17.6% and 14.7%, respectively), communication between physician and patient should focus on the reasons for the application of a T2T strategy and on the balance of benefits and risks of initiating treatment with a particular immunosuppressive agent for the individual patient. In particular, the need for close monitoring aiming at the achievement of remission and the prevention of irreversible disease- and treatment related damage should be

Table II. Regression analyses to identify parameters influencing the extent of shared decision-making adjusted for age and gender (Each row in the univariate analysis column shows the results of a separate analysis).

	Univariate analyses			Multivariate analysis		
	Estimate	CI 95%	*p*-value	Estimate	CI 95%	*p*-value
Disease duration	**0.21**	**0.14 to 0.28**	**<0.001**	**0.13**	**0.07 to 0.19**	**<0.001**
Origin (compared to German)						
Dutch	**0.06**	**0.41 to 0.80**	**<0.001**	**0.30**	**0.13 to 0.48**	**<0.001**
Bulgarian	-0.19	-0.40 to 0.02	0.08	-0.13	-0.31 to 0.06	0.18
Austrian	-0.06	-0.43 to 0.31	0.75	-0.04	-0.37 to 0.29	0.80
Self-reported remission						
Not in remission	**-0.52**	**-0.69 to -0.35**	**<0.001**	**0.07**	**-0.11 to 0.24**	**0.46**
Uncertain remission status	**-0.84**	**-1.09 to -0.60**	**<0.001**	**-0.33**	**-0.56 to -0.10**	**0.004**
Satisfaction with health status	**0.34**	**0.27 to 0.40**	**<0.001**	0.04	-0-04 to 0.13	0.32
Satisfaction with treatment	**0.55**	**0.49 to 0.62**	**<0.001**	**0.46**	**0.37 to 0.55**	**<0.001**

CI: confidence interval.

addressed. Further, it should be mentioned, that the number of doctor visits will decrease, once stable remission is achieved.

In line with previous reports, the patients ranked the normalisation of QoL as the most relevant outcome (23), while the most important treatment goal for rheumatologists is remission. This finding indicates that to fully engage patients in the new T2T strategy, our treatment aims should extend beyond mere remission achievement to also include health-related QoL (HRQoL) in our assessments.

Encouragingly, previous analyses have shown that patients in remission experience improved physical HRQoL (24, 25), so that physician and patient-centered goals do not contradict but overlap. However, the correlation between remission and mental HRQoL is less consistent (24, 25). This finding indicates that a) mental HRQoL is probably influenced by disease activity to a lesser extent and that b) despite assessing remission, the incorporation of patient-reported outcome measures into clinical practice is important.

Correspondingly, the 2023 updated EULAR recommendations underscore the importance of a personalised treatment approach based on SDM and patient preferences in SLE patients (3). Besides the prevention of flares and organ damage, enhancement of QoL is named as long-term treatment goal in SLE, with strict adherence as prerequisite (3).

Adherence rates are often low in SLE patients, with intentional non-adherence stemming from factors such as fear of side effects of medication, disagreement over the necessity for medication, and mistrust towards the treating physician (14, 26). Overcoming these hurdles requires patient empowerment, information exchange, and the active involvement of individual patients through SDM, which has been shown to improve adherence (27). This process ensures both parties mutually agree upon decisions.

In our survey, the majority of respondents reported being somewhat to entirely involved in treatment decisions, although a fifth did not feel involved at all. Increased involvement in treatment decisions (improved SDM) was associated with longer disease duration, Dutch origin, self-reported remission and satisfaction with treatment. While the association with longer disease duration might be explained by higher self-esteem through many years of experience, this finding additionally shows that involvement in treatment decisions can lead to higher satisfaction and remission rates and/or *vice versa*. Accordingly, uncertainty with remission status was strongly associated with less involvement according to SDM.

A survey in rheumatoid arthritis patients has shown that, while some patients may prefer leaving treatment decisions to the rheumatologist, the overwhelming majority prefers to receive information about all treatment options, thereby being involved in decision-making (28). For these patients, successful T2T implementation requires SDM. Otherwise, the T2T strategy risks being undermined by increased non-adherence. Therefore, rheumatologists should be trained not only in management according to T2T but also in the principles and practical implementation of SDM. Decision aids can serve as useful tools to assist patients in making informed treatment choices. Accordingly, the updated 2023 EULAR recommendations for the management of SLE endorse SDM as an overarching principle (3), yet its practical implementation has not been evaluated.

The need for a T2T approach to enhance patient outcomes is underscored by the remission and satisfaction rates reported in our survey: Self-reported remission rates were comparable to those documented in extensive cohorts (9). However, a significant proportion (38.6%) of respondents reported not being in remission, and 29.3% expressed little or no satisfaction with their current health status. Treatment satisfaction was notably higher, with only 14.8% of participants expressing little or no satisfaction with their treatment. Equally important to T2T is an inclusive approach that allows patients to voice their concerns and personal objectives, thereby potentially increasing overall satisfaction.

Although not a validated target, satisfaction with health status and treatment could be seen as the ultimate patient-centered goal. Satisfaction rates appear to escalate with extended disease duration, potentially due to increased familiarity and acceptance of the disease over time. Furthermore, Dutch SLE patients reported higher satisfaction regarding their health status and treatment and felt more frequently engaged in treatment decisions. Given their longer disease duration with regard to patients from Germany, Bulgaria and Austria, we believe that this factor significantly contributed to the observed effect size. Beyond that, we cannot fully explain or verify this result, as we do not have access to the patients' medical records from this anonymous survey.

A limitation of this survey was the use of self-designed questions rather than a validated questionnaire. However, no validated questionnaire exists to assess advantages and disadvantages of SDM, especially since the implication of SDM varies with every disease. It was our aim to obtain a pattern of opinion to be considered for the implementation of T2T in SLE. Based on our findings, focus groups and other qualitative methods can be utilised to further elaborate the subject, as a means of preparation for the practical incorporation of T2T into clinical practice.

Given the distribution via SLE self-help organisations, we were unable to verify the diagnosis accepting the possibility of including non-SLE patients. Furthermore, only few disease characteristics were assessed, and we specifically did not ask for disease characteristics other than disease duration. However, we believe that the large number of patients included from 4 different countries helps to correct a potential bias caused by self-diagnosis and allows for generalisability among SLE patients, with the limitations that only patients from European countries were included.

While it is widely acknowledged that achieving and maintaining remission or low disease activity leads to better outcomes in terms of reduced damage accrual, morbidity, and mortality and enhanced HRQoL (9), there is currently no established strategic concept for actively treating to target.

Furthermore, it remains unclear whether actively treating to target yields different outcomes compared to reaching the target by standard of care. This will be further investigated in the ongoing Lupus-Best trial (NCT05714930).

In conclusion, the survey provides valuable insights into the demand for and acceptance of a T2T strategy in patients with SLE. A substantial number of patients are dissatisfied with their health status and do not consider themselves in remission. The T2T concept could increase remission rates and has been perceived largely positively with tailored treatments and potential reduction in glucocorticoid usage as the main advantages. It is evident that a T2T strategy for most patients requires SDM, necessitating a transformative shift in communication and patient education.

Acknowledgements

We sincerely thank the national patient organisations Nationale vereniging voor mensen met lupus (NVLE Netherlands), Lupus Erythematodes Selbsthilfegemeinschaft e.V., the Bulgarian Organisation for Patients with Rheumatic Diseases (BOPRD) and the Selbsthilfe Lupus-Austria as well as Boryana Boteva for distributing the survey, and all the patients for their participation.

References

1. SCHMEDING A, SCHNEIDER M: Fatigue, health-related quality of life and other patient-reported outcomes in systemic lupus erythematosus. *Best Pract Res Clin Rheumatol* 2013; 27(3): 363-75. https://doi.org/10.1016/j.berh.2013.07.009
2. BARBER MRW, FALASINNU T, RAMSEY-GOLDMAN R, CLARKE AE: The global epidemiology of SLE: narrowing the knowledge gaps. *Rheumatology* (Oxford) 2023; 62(Suppl 1): i4-i9. https://doi.org/10.1093/rheumatology/keac610
3. FANOURIAKIS A, KOSTOPOULOU M, ANDERSEN J *et al.*: EULAR recommendations for the management of systemic lupus erythematosus: 2023 update. *Ann Rheum Dis* 2024; 83(1): 12-29. https://doi.org/10.1136/ard-2023-224762
4. GRIGOR C, CAPELL H, STIRLING A *et al.*: Effect of a treatment strategy of tight control for rheumatoid arthritis (the TICORA study): a single-blind randomised controlled trial. *Lancet* 2004; 364(9430): 263-69. https://doi.org/10.1016/S0140-6736(04)16676-2
5. COATES LC, MOVERLEY AR, MCPARLAND L *et al.*: Effect of tight control of inflammation in early psoriatic arthritis (TICOPA): a UK multicentre, open-label, randomised controlled trial. *Lancet* 2015; 386(10012): 2489-98. https://doi.org/10.1016/S0140-6736(15)00347-5
6. SCOTT IC, IBRAHIM F, LEWIS CM, SCOTT DL, STRAND V: Impact of intensive treatment and remission on health-related quality of life in early and established rheumatoid arthritis. *RMD Open* 2016; 2(2): e000270. https://doi.org/10.1136/rmdopen-2016-000270
7. STOFFER MA, SCHOELS MM, SMOLEN JS *et al.*: Evidence for treating rheumatoid arthritis to target: results of a systematic literature search update. *Ann Rheum Dis* 2016; 75(1): 16-22. https://doi.org/10.1136/annrheumdis-2015-207526
8. ZUCCHI D, CARDELLI C, ELEFANTE E, TANI C, MOSCA M: Treat-to-target in systemic lupus erythematosus: reality or pipe dream. *J Clin Med* 2023; 12(9): 3348. https://doi.org/10.3390/jcm12093348
9. YANG Z, CHENG C, WANG Z *et al.*: Prevalence, predictors, and prognostic benefits of remission achievement in patients with systemic lupus erythematosus: a systematic review. *Arthritis Care Res* (Hoboken) 2022; 74(2): 208-18. https://doi.org/10.1002/acr.24464
10. VAN VOLLENHOVEN RF, BERTSIAS G, DORIA A *et al.*: 2021 DORIS definition of remission in SLE: final recommendations from an international task force. *Lupus Sci Med* 2021; 8(1). https://doi.org/10.1136/lupus-2021-000538
11. FRANKLYN K, LAU CS, NAVARRA SV *et al.*: Definition and initial validation of a Lupus Low Disease Activity State (LLDAS). *Ann Rheum Dis* 2016; 75(9): 1615-21. https://doi.org/10.1136/annrheumdis-2015-207726
12. GOLDER V, OOI JJY, ANTONY AS *et al.*: Discordance of patient and physician health status concerns in systemic lupus erythematosus. *Lupus* 2018; 27(3): 501-6. https://doi.org/10.1177/0961203317722412
13. COSTEDOAT-CHALUMEAU N, AMOURA Z, HULOT J-S *et al.*: Very low blood hydroxychloroquine concentration as an objective marker of poor adherence to treatment of systemic lupus erythematosus. *Ann Rheum Dis* 2007; 66(6): 821-24. https://doi.org/10.1136/ard.2006.067835
14. HARDY C, GLADMAN DD, SU J, ROZENBOJM N, UROWITZ MB: Barriers to medication adherence and degree of nonadherence in a systemic lupus erythematosus (SLE) outpatient population. *Rheumatol Int* 2021; 41(8): 1457-64. https://doi.org/10.1007/s00296-021-04898-0
15. SMOLEN JS, LANDEWÉ R, BIJLSMA J *et al.*: EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update. *Ann Rheum Dis* 2017; 76(6): 960-77. https://doi.org/10.1136/annrheumdis-2016-210715
16. SMOLEN JS, LANDEWÉ RBM, BERGSTRA SA *et al.*: EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2022 update. *Ann Rheum Dis* 2023; 82(1): 3-18. https://doi.org/10.1136/ard-2022-223356
17. HARROLD LR, REED GW, JOHN A *et al.*: Cluster-randomized trial of a behavioral intervention to incorporate a treat-to-target approach to care of US patients with rheumatoid arthritis. *Arthritis Care Res* (Hoboken) 2018; 70(3): 379-87. https://doi.org/10.1002/acr.23294
18. CHAMBERS SA, RAINE R, RAHMAN A, ISENBERG D: Why do patients with systemic lupus erythematosus take or fail to take their prescribed medications? A qualitative study in a UK cohort. *Rheumatology* (Oxford) 2009; 48(3): 266-71. https://doi.org/10.1093/rheumatology/ken479
19. FORD JA, SOLOMON DH: Challenges in implementing treat-to-target strategies in rheumatology. *Rheum Dis Clin North Am* 2019; 45(1): 101-12. https://doi.org/10.1016/j.rdc.2018.09.007
20. KONERU S, KOCHARLA L, HIGGINS GC *et al.*: Adherence to medications in systemic lupus erythematosus. *J Clin Rheumatol* 2008; 14(4): 195-201. https://doi.org/10.1097/RHU.0b013e31817a242a
21. LEHANE E, MCCARTHY G: Intentional and unintentional medication non-adherence: a comprehensive framework for clinical research and practice? A discussion paper. *Int J Nurs Stud* 2007; 44(8): 1468-77. https://doi.org/10.1016/j.ijnurstu.2006.07.010
22. SMITH EMD, GORST SL, AL-ABADI E *et al.*: 'It is good to have a target in mind': qualitative views of patients and parents informing a treat to target clinical trial in juvenile-onset systemic lupus erythematosus. *Rheumatology* (Oxford) 2021; 60(12): 5630-41. https://doi.org/10.1093/rheumatology/keab173
23. KERNDER A, ELEFANTE E, CHEHAB G, TANI C, MOSCA M, SCHNEIDER M: The patient's perspective: are quality of life and disease burden a possible treatment target in systemic lupus erythematosus? *Rheumatology* (Oxford) 2020; 59: v63-v68. https://doi.org/10.1093/rheumatology/keaa427
24. MARGIOTTA DPE, FASANO S, BASTA F *et al.*: The association between duration of remission, fatigue, depression and health-related quality of life in Italian patients with systemic lupus erythematosus. *Lupus* 2019; 28(14): 1705-11. https://doi.org/10.1177/0961203319884651
25. MOK CC, HO LY, TSE SM, CHAN KL: Prevalence of remission and its effect on damage and quality of life in Chinese patients with systemic lupus erythematosus. *Ann Rheum Dis* 2017; 76(8): 1420-25. https://doi.org/10.1136/annrheumdis-2016-210382
26. GEORGOPOULOU S, NEL L, SANGLE SR, D'CRUZ DP: Physician-patient interaction and medication adherence in lupus nephritis. *Lupus* 2020; 29(10): 1168-78. https://doi.org/10.1177/0961203320935977
27. ZOLNIEREK KBH, DIMATTEO MR: Physician communication and patient adherence to treatment: a meta-analysis. *Med Care* 2009; 47(8): 826-34. https://doi.org/10.1097/mlr.0b013e31819a5acc
28. TORO J de, GONZÁLEZ CM, CEA-CALVO L *et al.*: Patients' perceptions on shared decision making during prescription of subcutaneous biological drug treatments for inflammatory arthritis: The RHEU-LIFE survey. *Musculoskeletal Care* 2020; 18(4): 568-74. https://doi.org/10.1002/msc.1499