

COVID-19 and Lupus and related diseases. Patients experience in Northern Ireland

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Background – Since the beginning of the Covid-19 pandemic concerns have been raised for rheumatology patients with connective tissue diseases. Connective tissue diseases and the immunosuppressant therapies placed many patients into the category of ‘clinically vulnerable group’ when the UK’s shielding guidance commenced on the 23rd May 2020. ‘Lockdown’ reduced the availability of face-to-face clinics, with more emphasis given to telephone consultation.

Objectives – The objective of the study was to evaluate impact of the pandemic on patients with connective tissue diseases. Questions focussed on the patient’s experience, clinical care and advice, disease activity, exercise, and mental health.

Methods - A web-based cross-sectional survey was completed in the Belfast health and social care trust, in Northern Ireland between 1st January 2021 and 1st February 2021. The survey was distributed via SMS invitation, and via social media platforms.

Results - There were 67 responses, with 1 omitted and 66 of them included in analysis. Most respondents had systemic lupus erythematosus (SLE) 87.5%, followed by mixed connective tissue disease (MCTD) (7.7%), undifferentiated connective tissue disease (UCTD) (1.5%). 98% of patients were female, aged between 25 and 77 years old. 96.9% of the respondents were Caucasian which reflects the general population of Northern Ireland¹. 63.2% of the respondents were under the care of rheumatology in the Belfast health and social care trust, followed by the Southern health and social care trust (15.8%).

The commonest medications taken were hydroxychloroquine (50.3%), followed by methotrexate and mycophenolate mofetil (4.8%). Of those on Biologics there were 11.2% (N=7) on rituximab, and 1.6% (N=1) on belimumab. Only 7.8% (N=5) patients stopped the treatment during the lockdown and of those patients 62.5% (N=5) stopped their meds longer than 6 months. 38.5% (N=5) of those that stopped their medication experienced a flare of their disease. 4 of these patients were receiving rituximab prior to lockdown and one was taking NSAIDs.

The majority were satisfied with clinical accessibility to rheumatology 81.5% (N=44), with most via the lupus clinical nurse specialist (CNS). Most 71% (N=47) had recently received a clinical review, with over half of these being a face-to-face clinician review. However, there was a 28% reduction in response to this question. Within the Belfast trust 63.5% of respondents had a review by the Lupus CNS, with most done via telephone review (76%). 53% (N=35) did not have any difficulty contacting their GP. Regarding the advice given to the respondents in relation to shielding, over a half (56.5%) felt the advice was clear. Most received advice was via a shielding letter (67.5%). Interestingly, just under two thirds of patients (61.7%) felt that the advice they received was not consistent from all sources.

Only 3.1% (N=2) of respondents tested positive for COVID-19. Neither of these patients were receiving biologics/DMARDs. Both did not require hospitalisation.

The shortened Warwick Edinburgh Mental Wellbeing Scale (WEMWBS)² was utilised to assess mental wellbeing. 29.7% (N=19) had low mental wellbeing, 43.8% (N=28) moderate and 30% (N=13) high. Of those respondents within the low mental wellbeing category only 31.6% (N=6) exercised 20-30 minutes daily and 47.4% (N=9) did no exercise at all. However, within the high mental wellbeing category, 66.7% (N=12) exercised 20-30mins daily and only 5.6% (N=1) did no exercise.

Conclusion The survey showed minimal levels of COVID-19 within the demographic with no hospitalisations, despite continuing immunosuppressant therapies. Despite good accessibility to rheumatology services, patient's felt shielding advice was inconsistent between sources. Few patients stopped immunosuppressant treatments for a prolonged duration, and good rheumatology service accessibility. The survey findings indicated that stopping medication has a have a negative impact on disease control. The survey has established a link between low levels of exercise and low mental wellbeing. This correlates with the link between deteriorating mental health and increase in disease activity in SLE.

References

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