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AGENTS WITH RHEUMATIC DISEASES RECEIVING BIOLOGICAL

The incidence of COVID-19 among children

required for future increases in COVID infection rates. Further work in the older age groups. These data indicate a focus on adverse

as might be expected, physical health scores were significantly worse

mental health scores between patients in different ages groups, while,

There was no significant difference in

We found significantly worse mental health scores in female patients,

patients had lower PCS (-2.7, \( P < 0.001 \)) and PCS (-3.1) (both \( P < 0.001 \)). Older

COVID had lower MCS (-2.1) and PCS (-3.1) (both \( P < 0.001 \)).

patients were analysed using SPSS version 26.

Survey responses were received from 1,828/7,911 (23%) and of these

1,727 completed all aspects of the SF12. Responders were mostly

white British 1,711/1828 (94%) and female 1,276 (70%); inflammatory

1,727 reported having suffered COVID-19 infection. Mental SF-12

were assessed patient's HRQoL by Short Form-12 version 2 (SF12); data

From patient charities and four expert patients. The survey was hosted

about the degree and severity of COVID-19 among children suffering

with COVID-19, but we suppose it is too early to make conclusions

Over the past period (32 weeks of follow-up) 3% of children with

biological agents there were no registered severe cases of COVID-19.

Conclusion

FUTURE CARE: A NATIONWIDE STUDY OF MORE THAN 2,000 PATIENTS

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Background/Aims

The COVID-19 pandemic is associated with significant levels of

psychological distress, affecting both those with and without the

recognised that extra precautionary measures in this group, such as

rheumatology patients are 'clinically extremely vulnerable', classed as

Asian and ethnic minority groups (BAME). A significant proportion of

notably affected those who are female, in younger age groups, black

We distributed a web-based survey via a linked mobile-phone SMS

impacted, have not being explored. In our large cohort of rheumatol-

inflammatory

Results

from various rheumatic diseases and receiving therapy with anti-

an average age 10.3

erythematosus (SLE), 2 (1.6%) patients had juvenile dermatomyositis

juvenile idiopathic arthritis (JIA), 2 (1.6%) children had systemic lupus

had familial Mediterranean fever (FMF), 2 (1.6%) children had

had deficiency of adenosine deaminase 2 (DADA2), 1 (1%) child had TNF

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most common being: rheumatoid arthritis (48%), lupus (20%), Sjogren’s syndrome (19%), fibromyalgia (15%) and vasculitis (8%). More than half (57%) were told to shield, whilst 10% decided to shield of their own accord. Compared with before the pandemic, 57% felt it was difficult/very difficult to contact their rheumatologist. Regarding treatment, 15% reported difficulty obtaining their usual medication. Less than half (45%) of patients continued medication as previously and had no problem accessing it, although 21% said their usual drug monitoring had been discontinued. Overall, 3% stopped their treatment of their own accord. In all, 26% said their appointments in rheumatology clinics had been cancelled and they did not know when they would be seen again (4% reported no change in their outpatient follow-up). Prior to the pandemic, 13% of patients had received a telephone consultation, however, since the pandemic 60% had received one. Just 19% felt it was easy to be honest with their clinician via telephone. Only 33% were satisfied with the current level of care, 43% reported their rheumatology care was worse than pre-pandemic and 38% of patients felt they needed to see their rheumatologist but could not get an appointment. Over half (67%) of patients expressed worries about their future care. If offered an appointment in the next few months 66% said they would prefer it be face-to-face.

**Conclusion**
To our knowledge, this study is the largest survey of patient experiences of the COVID-19 pandemic under rheumatological care anywhere in the world. We found more than half of patients were told to shield and one-in-ten decided to shield without being directly told to do so. Less than half of patients maintained relatively good access to their usual medication without necessary monitoring in many cases. In particular, patients express high levels of concern about their future care. These high levels of disruption indicate the importance of maintaining routine rheumatology services during the ongoing pandemic.

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