

Concise report

COVID-19 and myositis – unique challenges for patients

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Abstract

Objective. The COVID-19 pandemic and the subsequent effects on healthcare systems is having a significant effect on the management of long-term autoimmune conditions. The aim of this study was to assess the problems faced by patients with idiopathic inflammatory myopathies (IIM).

Methods. An anonymized eSurvey was carried out with a focus on effects on disease control, continuity of medical care, drug procurement and prevalent fears in the patient population.

Results. Of the 608 participants (81.1% female, median (s.d.) age 57 (13.9) years), dermatomyositis was the most frequent subtype (247, 40.6%). Patients reported health-related problems attributable to the COVID-19 pandemic ($n = 195$, 32.1%); specifically 102 (52.3%) required increase in medicines, and 35 (18%) required hospitalization for disease-related complications. Over half (52.7%) of the surveyed patients were receiving glucocorticoids and/or had underlying cardiovascular risk factors (53.8%), placing them at higher risk for severe COVID-19. Almost one in four patients faced hurdles in procuring medicines. Physiotherapy, critical in the management of IIM, was disrupted in 214 (35.2%). One quarter (159, 26.1%) experienced difficulty in contacting their specialist, and 30 (4.9%) were unable to do so. Most (69.6%) were supportive of the increased use of remote consultations to maintain continuity of medical care during the pandemic.

Conclusion. This large descriptive study suggests that the COVID-19 pandemic has incurred a detrimental effect on continuity of medical care for many patients with IIM. There is concern that delays and omissions in clinical care may potentially translate to poorer outcomes in the future.

Key words: myositis, COVID, coronavirus, pandemic, dermatomyositis, telemedicine

Introduction

There is a likely heightened risk of infection and/or associated complications from severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2, COVID-19) in patients with idiopathic inflammatory myopathies (IIM) and other autoimmune rheumatic diseases (RDs),

compared with individuals without such conditions [1]. The autoimmune nature of the diseases, use of immunosuppressive (IS) therapies, and/or associated cardiovascular or respiratory co-morbidities may all be contributory. Additionally, the uncertainties regarding the duration of the pandemic, and requirement for social distancing or self-isolation to mitigate infection risk, pose unique challenges for drug procurement and continuity of medical care.

In this context, we conducted an anonymized international eSurvey of patients with IIM, with a focus on potential effects on disease control, continuity of medical care, drug procurement and prevalent fears in the patient population during the pandemic.

Methods

Design of the questionnaire

The questionnaire featured 25 questions, most (20) of which were multichoice. While five items were to identify respondent characteristics, 20 pertained to domains such as hygiene and confinement practices, disease

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Rheumatology key messages

- Our survey highlights that COVID-19 has incurred a detrimental effect on patients with myositis.
- Difficulties in procuring medicines, delayed biologic infusions, and disrupted physiotherapy sessions were common.
- Such delays and omissions in clinical care may translate to poorer outcomes in the future.

status, drug procurement and e-consultations, comorbidities and prevalent fears.

Three rheumatologists and one undergraduate medical student reviewed the questions and confirmed them to be representative of the content validity of the survey. Following this, this survey was filled by three individual respondents to identify errors in wording, grammar or syntax, and critically evaluate face validity. The average survey time was seven minutes. The respondents could change the answers before submission but not after it. All questions (but one) were mandatory.

Population selection

The eSurvey was posted in English on various social media platforms (Facebook and Twitter using the hashtags #myositis and #Covid-19) from the authors as well as promoted by patient organizations including The Myositis Association (TMA) and Myositis UK. The survey link was shared with the participants on 14 April 2020, following which they were given three weeks' time to voluntarily complete the questionnaire. The introductory text of the survey said clearly that it is to be filled only by patients with a diagnosed form of inflammatory myositis. The survey response collection was closed on 4 May 2020. Informed consent was provided at the beginning of the survey and no incentives were offered for survey completion. An exemption from review was obtained from the institute ethics committee of Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow (2018-62-IP-EXP) as per local guidelines [2]. We adhered to the Checklist for Reporting Results of Internet E-surveys to report the data [3].

Data analysis

Descriptive statistics were used and values provided as median (inter-quartile range/%). Open ended responses in the 'Other' category were manually allocated to existent categories. Whenever they did not fit in an existent category, a new category was listed. Data was downloaded from surveymonkey.com into Microsoft Excel, and PowerPoint and SurveyMonkey platforms were used for designing the figures. Intergroup comparisons were done by geographic distribution (continent wise).

Results

Of the 608 participants [81.1% female, mean (s.d.) age was 57 (13.9) years], dermatomyositis was the most

common clinical patient-reported IIM subtype (247, 40.6%), followed by inclusion body myositis (141, 23.2%), polymyositis (87, 14.3%) and anti-synthetase syndrome (52, 8.6%, [Supplementary Table S1](#), available at *Rheumatology* online). The majority of participants lived in the USA (58.9%) and the UK (21.7%).

Disease status

Many patients experienced health-related problems during the pandemic ($n=195$, 32.1%). Over half of those (52.3%) required an increase in medication and 35 (18%) required hospitalization for disease-related complications ([Fig. 1](#)). Nearly one in six (13.1%) required an increase in glucocorticoids dose due to worsening disease activity. In addition, 93 patients experienced a variety of other symptoms that were either unrelated (33, 16.9%) or of unclear origin (60, 30.7%), as attributed by the respondent. The underlying IIM disease remained stable for the majority of patients who completed the survey (360, 59.2%).

Risk factors

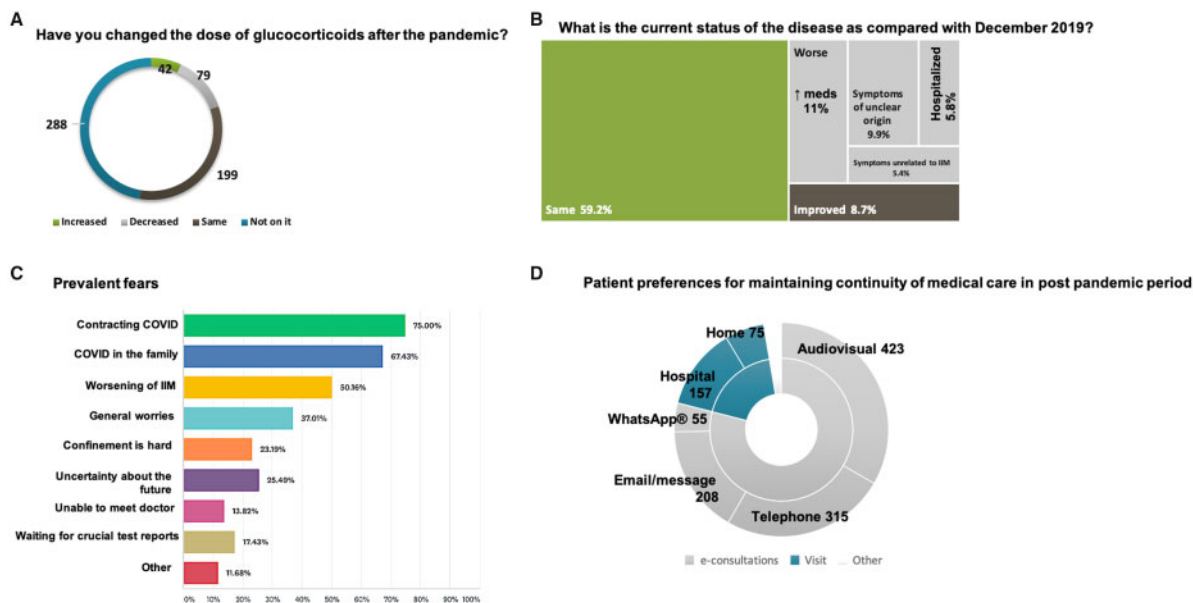
Over half (53.8%) of the IIM patients had underlying cardiovascular risk factors ([Supplementary Table S1](#), available at *Rheumatology* online) that would put them at higher risk for severe COVID-19 infection.

Over half (52.7%) of respondents were receiving glucocorticoids at the time of survey, which may further increase the risk for severe COVID-19.

Logistic challenges

Almost one in four patients (26.3%) faced hurdles in procuring medicines ([Supplementary Table S2](#), available at *Rheumatology* online). Of the 152 (25.6%) patients that were due for infusions, almost one in five (33, 21.7%) had to delay treatment and some (10, 6.5%) were still searching for an alternative. Scheduled physiotherapy sessions, critical for treatment of IIM, were disrupted in a significant proportion (214, 35.2%). One quarter (159, 26.1%) experienced difficulty in contacting their specialist, and 30 (4.9%) were unable to do so. The experience was similar with local practitioners ([Supplementary Table S2](#), available at *Rheumatology* online). Of the 160 who faced difficulty in getting their medication, 115 (71.8%) had to order medicines via alternative means, or sought help from family to get them (148, 92.5%), while 17 (10.6%) were forced to stop treatment due to the situation.

Fig. 1 Problems and prevalent fears among patients with myositis



Awareness and fears

IIM patients were in general well informed of how to decrease the risk of contracting COVID-19. Social distancing was practiced by nearly all (99.0%), and all had awareness of hand hygiene (100.0%). Three-quarters (454, 74.6%) wore masks, especially when visiting enclosed spaces. Contracting COVID-19 was the most prevalent fear (75.0%), followed by infection among the family members (67.4%) and a flare of disease (50.2%). General anxiety and difficulty in confinement were also common (37.0 and 23.2%, respectively).

Continuity of care in the post-pandemic period

Most respondents were supportive of increased use of remote consultations (69.6%) to maintain continuity of medical care during the pandemic (Fig. 1). Audio-visual consults were preferred (423, 69.6%) over telephone-based services (315, 51.8%). Fewer (25.8% and 12.3%) said they would prefer personal interactions by visiting the physician themselves and being visited by health care workers at home if the pandemic continued longer. The responses did not differ based on the geographical location.

Discussion

This survey suggests that the COVID-19 pandemic has incurred a detrimental effect on a large proportion of patients with IIM. One-third experienced worsening in their health related symptoms, of which, half required an increase in medicines, and one in ten required hospitalization. Almost a quarter faced difficulty in procuring medicines and delayed infusions due to logistic issues,

and physiotherapy sessions were disrupted in over one-third. Thus, there is concern that such delays and omissions in clinical care may potentially translate to poorer outcomes in the future. Our large survey reports the first description of indirect morbidity in patients with IIM due to the COVID-19 pandemic.

Worsening of disease due to a virus-triggered cytokine storm remains a major concern among rheumatologists [1, 4–5]. Managing flares would potentially require higher doses of immunosuppression, potentially leading to higher risk of COVID-19. Moreover, the older population in IIM also has higher comorbid cardiovascular conditions, further adding to the risk. Although the results describe logistic issues in procuring drugs and poor health in a proportion during the early pandemic period, the lack of an adequate comparison group at non-pandemic times limits firm conclusions.

While the importance of a formal clinical exam cannot be over emphasized, challenging circumstances may suggest a need for shift to virtual consulting [6]. High levels of enthusiasm for teleconsultations were reported, although there remain challenges in accurately assessing disease activity using this novel approach. Remote consultations may be safer, more economically viable, and may also signal a shift towards patient-reported outcome measures, which can be conveniently transitioned into, with the appropriate use of pre-existent mobile application (app)-based symptom trackers [7, 8]. Community paramedicine and/or mobile integrated health care programs can also contribute [6]. In countries with established infrastructure, linking a mobile app-based symptom tracker with the hospital-based electronic health records would provide novel pathways for providing care to chronic autoimmune disease patients [6].

The long-projected duration of the pandemic mandates a logical solution for infusions to reduce hospital visits. The challenge of administering infusions could be overcome by shifting to home-based subcutaneous drug administration where feasible, as has been recently tried in France for cancer patients [9]. Widespread concerns and emerging evidence of prevalent anxiety and worsening population mental health during the global pandemic suggests a greater focus on anxiety management with cognitive behaviour therapy perhaps being fruitful in preparing individuals for the difficult times ahead.

A strength of our survey is this is the first step towards understanding prevailing disease conditions and challenges by IIM patients in the times of COVID-19. The survey also describes the prevalent practices and fears in a large number of IIM patients globally. Our study has several limitations, including that responses are subject to biases inherent to a self-report questionnaire, survivorship and recruitment bias, and respondents with a relatively higher socioeconomic status with a greater online presence. It is noted that studies of this nature are subject to sampling bias. Given the nature of the study, patient-reported diagnoses were not verified. Moreover, the survey language restricted representation from the non-English speaking world, limiting wider assessment of patient perspectives. Furthermore, data protection laws limiting the usage of SurveyMonkey in certain countries may have limited responses from those regions. We hope to have balanced the requirements for rapid conduct of this survey in the face of the global pandemic against the need to minimize sampling bias. Moreover, our approach has the benefit of involving large numbers of patients in different countries, not otherwise feasible by other means currently.

Overall, our analysis highlights the significant challenges facing healthcare systems worldwide in the long-term management of patients with IIM. In addition to the direct response to the pandemic, mitigating the indirect negative impact is vital, e.g. delayed appointments, diagnostics and treatments, which may all lead to poorer outcome. Any response to the pandemic must also consider these indirect consequences and the potential changes to working practices, including increased use of remote consultations, which might be required for continuity of patient care. Moreover, mirroring the learning, experience and success in managing IIM in the prevailing circumstances may find utility in other RDs.

This large descriptive study suggests that the COVID-19 pandemic has incurred a detrimental effect on continuity of medical care for many patients with IIM. There is concern that delays and omissions in clinical care may potentially translate to poorer outcomes in the future.

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Supplementary data

Supplementary data are available at *Rheumatology* online.

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